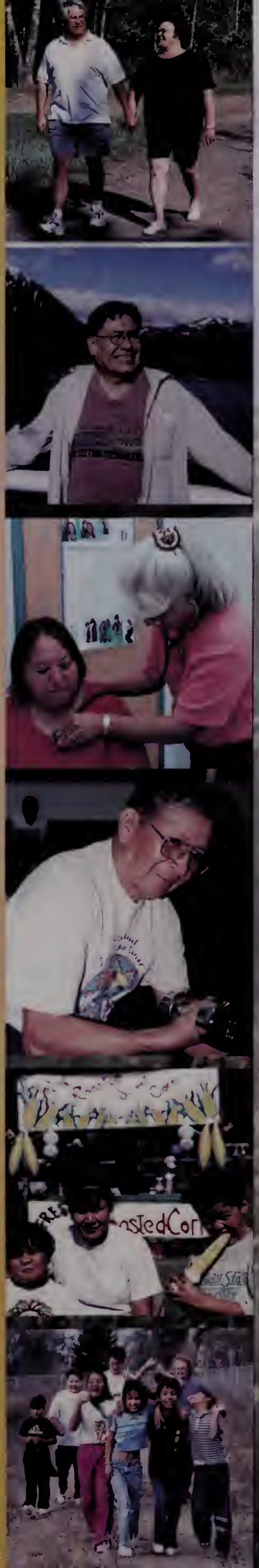

MEASURING DIABETES CARE

Improving Data Quality and Data Use in American Indian and Alaska Native Communities

Edited by
Charlton Wilson, MD
Anthia Reagan Nickerson

MH13D1205!

Measuring Diabetes Care: Improving Data Quality and Data Use in American Indian and Alaska Native Communities

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The opinions expressed in this report reflect those of the authors and do not necessarily reflect the views of the Indian Health Service.

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List of Abbreviations

The following abbreviations are frequently used throughout this report.

American Association of Clinical Endocrinologists ..... AACE

American Indian and Alaska Native ..... AI/AN

American Indians and Alaska Natives ..... AI/ANs

Centers for Disease Control and Prevention ..... CDC

Certified Diabetes Educator ..... CDE

Computerized Provider Order Entry ..... CPOE

Contract Health Service ..... CHS

Department of Health and Human Services ..... DHHS

Diabetes Management System ..... DMS

Electrocardiogram ..... EKG

Early Treatment Diabetic Retinopathy Study ..... ETDRS

End-stage Renal Disease ..... ESRD

Fiscal Year ..... FY

Glomerular Filtration Rate ..... GFR

Government Performance and Results Act ..... GPRA

Graphic User Interface ..... GUI

Indian Health Diabetes Care and Outcomes Audit ..... diabetes audit

Indian Health Performance Evaluation System ..... IHPES

Indian Health Service ..... IHS

Indian Health Service, tribal, and urban Indian ..... I/T/U

Institute of Medicine ..... IOM

Intensive Care Unit ..... ICU

Joint Commission on Accreditation of Healthcare Organizations ..... JCAHO

Kidney Disease Outcomes Quality Initiative ..... K/DOQI

National Kidney Foundation ..... NKF

Northwest Portland Area Indian Health Board ..... NPAIHB

Patient Care Component ..... PCC

Phoenix Indian Medical Center ..... PIMC

Resource and Patient Management System ..... RPMS

Introduction

Introduction

Measuring Diabetes Care: Improving Data Quality and Data Use in American Indian and Alaska Native Communities was a conference held in Seattle, Washington, on August 20–22, 2002. The conference was sponsored by the Indian Health Service (IHS) National Diabetes Program and Information Technology Support Center and was coordinated by the Northwest Portland Area Indian Health Board. The purpose of the conference was to discuss methods to improve the quality and expand the use of data for individual patient care and population-level purposes. Also, the conference organizers hoped to chart out a vision for the future of improving diabetes data use.

The purpose of this conference report is to document conference action items and conference participants' vision for diabetes data with the hope that this information will encourage people working in American Indian and Alaska Native (AI/AN) communities to increase their use of diabetes data. By increasing the use of diabetes data, AI/AN communities will be better equipped to care for people who have or are at-risk for diabetes.

The conference was a continuation of a series of grass roots meetings and sessions that explored strategies to improve data quality and use in AI/AN communities. Notably, in January 2000 in Phoenix, Arizona, and again in November 2000 in Albuquerque, New Mexico, small groups of staff and providers from various IHS, tribal, and urban Indian health programs met to develop data recommendations for the IHS National Diabetes Program. The recommendations from the workgroup resulted in an increase in the use of data for improving diabetes care in AI/AN communities throughout the U.S. Many of the recommendations had their origins from people who were working in the field, and these recommendations now have been enveloped into IHS data processes. The Seattle conference aimed to gather a large number of people working in AI/AN health care to generate more ideas about how we can use diabetes data to improve care for AI/AN communities.

Background

The IHS, an agency within the U.S. Department of Health and Human Services, was established in 1955 as the principal federal health care provider and health advocate for AI/ANs. The IHS provides health services to AI/ANs as a result of the trust responsibility of the federal government to provide health care for AI/ANs. This trust responsibility has been reaffirmed through treaties, multiple Supreme Court decisions, and specific Indian health legislation, including the Snyder Act of 1921 and the Indian Health Care Improvement Act of 1976 (P.L. 94-437).

The mission of the IHS is to raise the physical, mental, social, and spiritual health of AI/ANs to the highest level. The agency is a comprehensive, primary health care system of hospitals and clinics located on or near reservations in 35 states. The IHS is composed of 84 Service Units spread throughout 12 administrative Areas, which collectively serve 1.5 million AI/ANs, many of whom rely on it as their only source of health care coverage. The IHS provides direct primary care, referrals for specialty care, and public health services. Since passage of the Indian Self-Determination and Education Assistance Act of 1975 (P.L. 93-638), tribes can enter into

agreements (i.e., contracts or compacts) with the federal government to manage their own health programs that were previously managed by the IHS. In FY 2002, tribes managed 46% of the IHS budget. The IHS also provides funding for 34 urban Indian organizations to provide health services to AI/ANs living in urban areas.

Uses of data

Within the federal government, the IHS has been at the forefront in the development and use of data systems for health care statistics. The IHS has a long history in the development of information systems that have been a mainstay not only for the clinical management of health care, but also for the advocacy of health care programs.

Various types of data are used by different groups for a variety of reasons. Data collection and research can be used to measure health disparities, which provide powerful information to convince Congress and the American public that funding for AI/AN health must be increased to bring the health status of AI/AN communities to the level of the rest of the U.S. population. Policy makers need information on the demographics and health status of AI/ANs to identify unmet needs, monitor health status over time, and take responsibility for funding services at an appropriate level. Health care managers need information to assess the quality of care and health outcomes, so that they can identify opportunities for improvements in their health care systems. They also need information on the costs of delivering services and revenues, in order to maximize the resources available to meet local needs. Health care providers need research to understand the best strategies to prevent and treat diseases in the most effective and culturally competent ways. And, consumers need information and education that translate medical research into an accessible format that allows them to make informed choices about their lifestyles and treatment plans.

Data can also assist in a wide variety of important functions:

- Patient management
- Budget formulation, presentation, and justification
- Program planning and evaluation
- Resource management
- Determination of health education, protection, treatment, and preventive service needs
- Determination of the level of access to health care services
- Assessment of the health status of a community

In addition, data provide information on outcomes and support accountability in the use of funds. Through data, the IHS is able to provide this type of information in reports mandated by Congress, annual publications such as *Trends in Indian Health* and *Regional Differences in Indian Health*, and special reports such as *Indian Health Focus: Women* and *Indian Health Focus: Youth*.

Resource and Patient Management System (RPMS)
The IHS currently collects data on the health care services provided by IHS and tribal programs. The software used by IHS facilities and most tribal facilities is RPMS. Patient-specific data is collected through the Patient Care Component (PCC) of RPMS for each in-patient discharge, ambulatory medical visit, and dental visit. Other parts of RPMS provide data collection on demographics and alternate resources, as well as community health service programs, including health education, community health representatives, environmental health (e.g., safe drinking water and sanitation facilities), diet and nutrition, public health nursing, mental health and social services, and substance abuse.

Each local facility that utilizes the PCC system has a facility-level database containing the detailed PCC data collected at that site. A subset of this detailed PCC data is transmitted to the IHS central database to meet the needs of IHS Headquarters in planning, budgeting, and advocating for improvements in Indian health care.

Conference objectives and format

A conference planning committee composed of members from the IHS, National Institutes of Health, Centers for Disease Control and Prevention, and Northwest Portland Area Indian Health Board developed the objectives, themes, and format for the conference. The planning committee included the following members:

- Kelly Acton, MD, MPH
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- Nilka Rios-Burrows, MPH
  IHS
  Centers for Disease Control and Prevention Division of Diabetes Translation
- Theresa Cullen, MD, Planning Committee Co-Chair
  IHS Information Technology Support Center
- Kelly Gonzales, MPH
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  National Institutes of Health

- Robert Nelson, MD
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- Ray Shields, MD
  IHS Consultant
- Lorraine Valdez, RN, CDE
  IHS National Diabetes Program
- Charlton Wilson, MD, Planning Committee Co-Chair
  IHS Phoenix Service Unit, Phoenix Indian Medical Center

The objectives for the conference were to:

- Describe the importance and potential uses of diabetes data for individual patient care and for population-based reporting.
- Examine the current knowledge of data quality and data systems in a variety of different settings.
- Provide opportunities for beginning, intermediate, and advanced users of data to learn about data systems, describe their data use, compare data quality, receive peer feedback, and provide direction to the continued use of data systems.

To achieve these objectives, the conference was organized into three types of sessions:

- Plenary sessions: During the plenary sessions, conference participants received a broad overview of diabetes data and improvements in quality of care by leaders in tribal communities, the IHS, and outside the IHS.
- Workshops: The workshops focused on more specific issues related to diabetes data. The workgroup sessions were divided two different tracks—a basic/beginner track and an intermediate/advanced track—to allow conference participants the opportunity to tailor the conference to their needs.
  - The basic/beginner track (Level I) was designed to provide conference participants with an understanding of the currently available data and surveillance systems supported by IHS. Topics for the basic/beginner track included establishing a diabetes registry, using EpiInfo, and using the diabetes management system.
  - The intermediate/advanced track (Levels II and III) was designed to help conference participants tackle barriers that limit the use of data for individual patient care and population-based reporting. This track focused on data quality studies, data processes, and assessments of outcomes. Some of the workshops were demonstrations of new applications like PCC +, whereas other sessions were demonstrations from the field (e.g., speakers discussed how they are using data in their own communities).

- Workgroup sessions: Also in the intermediate/advanced track, the workgroup sessions focused on issues related to developing accurate estimates of the incidence and prevalence of diabetes. Rates of diseases are usually reported as the number of cases (numerator) per number of people in the community at risk (denominator, usually population number) at one point in time (prevalence) or over a certain period of time (incidence). Specifically, the workgroups developed strategies and recommendations on how to address the numerators and denominators. The numerator workgroups focused on clinical elements, such as foot care, eye care, cardiovascular care, chronic kidney disease, and patient education documentation. The denominator workgroups focused on prevalence, audit, and registry definitions. On the final day of the conference, the numerator and denominator workgroups held a final session to lay out a vision and series of proposed activities that will help AI/AN communities use data to improve diabetes care.

Conference participants

The conference brought together several key groups of stakeholders working in AI/AN communities:

- *Researchers* from various disciplines, such as epidemiology, statistics, health care outcomes, and public policy
- *Administrators and professionals*, such as clinic administrators, health records professionals, and information technology specialists, who are responsible for tracking and maintaining data
- *Community members and leaders*, such as tribal leaders and tribal health directors
- *Health care professionals*, such as diabetes coordinators and physicians

In total, 180 people attended the conference. Based on evaluations from the conference, participants indicated that they gained new knowledge, skills, and ideas about how data for diabetes can be used in medical care settings. Perhaps the most important result of the conference was that participants noted that the conference motivated them to improve diabetes data collection at their sites. As one participant noted, "More than anything, I learned the capacity of data to capture trends and valuable data…. I was validated in my realization of what I need to learn to best utilize the resources that are available…. Don't let this be the only conference—it's just the beginning…"

Sources

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Plenary Sessions

Plenary Session

The History of Data in the IHS National Diabetes Program: The Beginning through the *Special Diabetes Program for Indians*

Kelly Acton, MD, MPH
Director, National Diabetes Program
Indian Health Service

Purpose

To review the history of the Indian Health Service (IHS), including the IHS National Diabetes Program, Diabetes Standards of Care, Diabetes Care and Outcomes Audit, and *Special Diabetes Program for Indians*. To summarize the Diabetes Prevention Project and review future directions for primary prevention and uses of data.

History of the IHS

The provision of health services to members of federally-recognized tribes grew out of the special government-to-government relationship between the federal government and Indian tribes. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. Treaties between the federal government and Indian tribes often called for the provision of medical services, the services of a physician, or perhaps the establishment of a hospital. However, until the Snyder Act of 1921, legislation for Congress to appropriate funds specifically for Indian health did not exist. The Snyder Act of 1921 was the principal legislation authorizing federal funds for health services to recognized Indian tribes by providing "for the relief of distress and conservation of health…[and]…for the employment of…physicians...for Indian tribes throughout the United States." The Snyder Act, along with the Indian Health Care Improvement Act of 1976, comprises the basic legislative authority for the health care programs that are administered by the IHS. The Indian Health Care Improvement Act was enacted into law in 1976 based upon findings that the health status of AI/AN communities continued to rank far below that of the general population.

The IHS was established in 1955 as the principal federal health care provider and health advocate for American Indians and Alaska Natives (AI/ANs). The mission of the IHS is to raise the physical, mental, social, and spiritual health of AI/ANs to the highest level and to ensure that comprehensive and culturally-acceptable personal and public health services are available. The foundation is to uphold the federal government's obligation to promote healthy AI/AN communities and to honor and protect the inherent sovereign right of tribes.

Approximately 50% of the estimated 2.6 million AI/ANs rely on the IHS as the *only* source of their health care coverage. The IHS, in partnership with tribes and AI/AN organizations through contracts and compacts, has developed an Indian health system of programs, facilities, and public health activities. The IHS is comprised of 84 Service Units spread throughout 12 administrative Areas located in 35 states. The agency provides services directly through inpatient and

outpatient facilities, or through tribally-contracted and operated health programs. In some places, much of the health care has been purchased from private providers from around the country. The IHS has 36 hospitals, 13 of which are tribal, and over 500 outpatient facilities. Because the IHS is predominantly a rural health care system, 60% of its hospitals and clinics are located in remote areas. In addition, 34 urban Indian health centers provide a variety of health and referral services to AI/ANs who live in urban areas. The IHS clinical staff consists of approximately 2,672 nurses, 921 physicians, 353 engineers, 438 pharmacists, 319 dentists, 142 sanitarians, and approximately 230 registered dietitians. In addition, the IHS employs various allied health professionals, such as physical therapists, health administrators, and medical records administrators. The IHS currently has an approximate 12% vacancy rate among all health professionals, with critical shortages in nursing, oral health (dentists), nutrition, and behavioral health. With its emphasis on primary care and prevention, the IHS also provides a range of public health programs, such as the construction of water and sanitation projects.

The IHS National Diabetes Program

The Indian Health Care Improvement Act of 1976 is the foundation for the IHS National Diabetes Program. The goal of the Act is to provide for the quantity and quality of health services necessary to elevate the health status of AI/ANs to the highest possible level and to encourage the maximum participation of tribes in the planning and management of those services. In the 1970s, the National Commission on Diabetes identified diabetes as a growing problem among AI/AN communities and recommended to Congress that a special program be set up within the IHS to address diabetes. In 1979, Congress authorized a national office to administer a diabetes program. The program was established that year at IHS Headquarters West in Albuquerque, New Mexico. Over time, Congress stipulated that this office would conduct surveillance and evaluation activities, establish Model Diabetes Programs in 19 sites identified in the legislative language, and employ Area Diabetes Consultants in all 12 Areas.

Although the IHS had a lot of success in treating infectious diseases, establishing and developing a program to address a chronic disease was a challenge for the IHS. Other challenges included:

- Improving awareness: Tribes and clinicians were not aware that diabetes was a widespread problem; many thought it was isolated to communities such as the Pima Indians of Arizona.
- Providers did not know how to treat the disease: At the time, providers addressed diabetes purely through a clinical approach.
- Lack of adequate data and surveillance: We did not know how big the problem truly was.

To address these challenges, the IHS National Diabetes Program focused on surveillance and clinical care of diabetes. The surveillance system that we have developed over time has shown how diabetes prevalence for AI/AN communities is much greater than that of the general population and how the diabetes prevalence for AI/AN youth has increased over 100% in the last decade. The IHS depends upon the data that is collected at the local level to convince people at the national level that more resources are needed to address the problem of diabetes. In addition, some of the ideas that came out of the Model Diabetes Programs included resources that we take

for granted today, such as diabetes registries, flow sheets, specialized care, and clinics formed around diabetes.

As the IHS National Diabetes Program developed, the IHS created the Diabetes Standards of Care in 1986 to make care and treatment of diabetes consistent, becoming the first agency or organization in the nation to do so. The IHS Diabetes Standards of Care include demographic information; monitoring information; and clinical, preventive, and education measures.

Although the IHS Diabetes Standards of Care provided clinics with a benchmark for consistent diabetes care, the IHS still needed to measure the level of care and determine if various interventions were effective. Out of these needs, the IHS Diabetes Care and Outcomes Audit (diabetes audit) was born. The Aberdeen Area was the first IHS Area to participate in the diabetes audit in 1986. Currently, sites are not forced to participate in the diabetes audits; participation is voluntary. The nationwide diabetes audit currently has 87 process and outcome measures that are based on the IHS Diabetes Standards of Care. Using EpiInfo, a summary rate is constructed for each measure and reports are generated at the local (Service Unit), regional (Area), and national levels.

In the 2001 diabetes audit, 151 facilities participated and 16,798 charts were reviewed. Some highlights from the 2001 diabetes audit included:

- The continued reduction of A1c levels since 1994 in three age groups, translating into a significant reduction in morbidity and mortality.
- Rates for foot and eye exams have not changed significantly, indicating that this is an area for improvement.
- The use of ACE inhibitors has increased.
- Proteinuria rates have decreased.
- Diabetes education, particularly exercise education, has increased since 1997.

The diabetes audits tell a powerful and important story. The diabetes audits give us the opportunity to improve care, measure the effectiveness of our programs and interventions, and compare ourselves to national benchmarks. They also show us that although we have not yet met our goal to raise the health of AI/AN to the highest possible level, we do a pretty good job at delivering health care in an under-resourced system.

Also during the period before 1997, the IHS National Diabetes Program developed clinical and public health relationships. The program focused not only on physicians and patients, but also on nurses, pharmacists, Community Health Representatives, and diabetes educators. Another activity that developed during this period was the use of Staged Diabetes Management, a product of the International Diabetes Center, in IHS facilities. Because each local site was different, a one-size-fits-all approach was not appropriate; we needed to be able to customize care at each local site.

Special Diabetes Program for Indians

The Balanced Budget Act of 1997 established the *Special Diabetes Program for Indians*, which continues though the present day. This program has significantly changed the focus, direction, and activities of the IHS National Diabetes Program. The Balanced Budget Act funds were devoted to the treatment and prevention of diabetes and were distributed as grants to tribes and tribal consortia at a rate of $30 million per year for five years through FY 2002. In 2001, Congress added $70 million for FY 2001, $70 million for FY 2002, and $100 million for 2003, adding another full year to the program.

Some of the highlights from the *Special Diabetes Program for Indians* include the following:

- In 1998, two-thirds of the diabetes grant programs focused some or all of the funds on primary prevention. Many diabetes grant programs established multiple projects that included primary prevention, as well as secondary and tertiary prevention.
- Diabetes grant programs reported that in the first year they were able to establish many projects and offer services that did not exist before the Balanced Budget Act funds. This included establishing diabetes teams, clinics, and education programs; using diabetes registries and flow sheets; providing more foot and eye exams by specialists; providing newer diabetes medications; establishing diabetes awareness programs; and offering greater access to culturally appropriate education materials.
- Perhaps one of the most significant results of the diabetes grant programs was the partnership that developed among tribal leaders, community members, and health care providers.
- Improvements in clinical care were better than expected since many programs focused on primary prevention.
- Congress stated in the legislative language that the IHS was required to evaluate the program. The evaluation of the Special Diabetes Program for Indians includes collecting and analyzing both quantitative and qualitative data. We currently have a number of sources of data for the evaluation:
  - One national meeting and eight regional meetings in 1999 and 2000. During the meetings, the IHS National Diabetes Program asked diabetes grant programs to provide feedback.
  - The annual grant application kit includes an assessment and progress report that diabetes grant programs complete and send back to the IHS National Diabetes Program for evaluation.
  - Each diabetes grant program has completed a summary for a compendium report. The report includes information on the activities of the diabetes grant programs that have not been captured in the quantitative and qualitative surveys.
  - To obtain information on clinical care at each diabetes grant program, the IHS National Diabetes Program has developed a cross-walk between the diabetes grant programs and the diabetes audits.

- Congress instructed the IHS to use a best practices approach. The IHS National Diabetes Program gathered people from all over the country to develop a plan to describe the best practices for the Indian health system and measure best practices activities. Some of these activities are easy to measure, such as foot care, eye care, and other measurements included in the diabetes audit. Other measurements are more difficult to measure, such as self-care management, school health, community advocacy, and systems of care.

Data issues in the IHS National Diabetes Program

A main challenge in data that currently faces the IHS National Diabetes Program is our progression from a manual audit to an electronic audit. This will require the following:

- We need to spruce up the Resource and Patient Management System (RPMS).
- We need to continue to focus on our definitions and cut points because our methods for measuring care need to keep up with the most recent scientific advances.
- We need to keep our data consistent on the national level.
- We need to improve training at the local level. One of the most successful outcomes of the regional epidemiology centers are the technical assistance programs that they have developed. The programs involve training staff at local clinics on using computers and software to collect diabetes data.
- We need to continue to build upon partnerships to improve data.

Diabetes Prevention Program (DPP)

The DPP was a randomized, controlled trial funded by the National Institutes of Health in 27 sites around the country. The study included an American Indian center that was comprised of Zuni, Shiprock, Gila River, Salt River, and the Phoenix Indian Medical Center. The purpose of the study was to determine if diet and exercise or metformin could prevent or delay the onset of type 2 diabetes. Overall, 3,234 overweight participants who had impaired glucose tolerance, now called prediabetes, were included in the study. The average age of the participants was 51 years old. Forty-five percent of the participants were from ethnic minority groups, including 171 AI/ANs.

The researchers randomized patients into either the lifestyle intervention arm, metformin arm, or placebo arm. The lifestyle intervention included reduced fat and calorie intake, 150 minutes of physical activity per week, and 7% loss of body weight if the participant was overweight. The metformin arm included use of metformin for people who had prediabetes. Metformin is currently approved for and used to treat type 2 diabetes, but the DPP was the first time that metformin was used in people with prediabetes.

The DPP ended a year early because results were so compelling. The results were published in the February 2002 issue of the *New England Journal of Medicine*. The lifestyle intervention group substantially reduced their risk of getting type 2 diabetes by 58%. The metformin group reduced their risk of developing type diabetes by 31%. (A post-DPP study is currently underway

to follow the participants.) In addition, the study found that people over 60 years old who were in the lifestyle intervention group reduced their risk of getting type 2 diabetes by 71%. Metformin was found not to be effective for older age groups or people who were not overweight. Rather, the medication was determined to be more effective in the younger age groups and people who are overweight.

The results of the DPP give us hope for our communities. Science once told us we could *treat* diabetes, but now science says that we can *prevent* diabetes. These encouraging results, however, bring up several important questions and issues for our diabetes programs:

- How can we measure primary prevention?
- How do we find people with prediabetes?
- How do we screen for them in a way that does not take resources away from treatment and intervention?
- How can we enhance our lifestyle programs and case management approach?
- We need to purchase metformin, but our pharmacy budget is extremely limited.

Our long-term plans need to include screening programs, lifestyle programs, and asking our partners and programs to advocate to Congress for additional funds to purchase metformin and purchase lifestyle program equipment and training.

Plenary Session

Diabetes Prevalence Statistics in the Indian Health Service

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Purpose

To describe the Memorandum of Agreement between the Centers for Disease Control and Prevention (CDC) Division of Diabetes and the Indian Health Service (IHS) National Diabetes Program for diabetes surveillance; review select data on diabetes prevalence in American Indians and Alaska Natives (AI/ANs); and describe how the data are used and disseminated.

Collaboration between the IHS and CDC

The CDC Division of Diabetes and the IHS National Diabetes Program have entered into a Memorandum of Agreement that provides for ongoing collaboration on the surveillance of diabetes and diabetes-related complications among AI/ANs. As a result, I have worked with the IHS National Diabetes Program to document the large and disproportionate burden of diabetes among AI/ANs and the increasing trend in diabetes prevalence, particularly among AI/AN youth.

Diabetes prevalence calculations: Numerators, denominators, and adjustments

When calculating the prevalence of diabetes, I use a numerator and two denominators (one denominator for the service population and one for the user population). Table 1 summarizes the definitions for the numerator and denominator:

Table 1. Definitions for numerators and denominators

Numerator	Denominator: Service Population	Denominator: User Population
The number of diabetes cases identified from the Resource and Patient Management System (RPMS) in one fiscal year	Population of AI/ANs who are eligible for IHS service based on U.S. Census data	Population of AI/ANs who are eligible for IHS, tribal, or urban Indian organization (I/T/U) services
The diabetes cases had an ICD-9 code of 250.0–250.9 as their purpose of visit	Population resides on IHS contract health service delivery areas	Population that received I/T/U services at least once during the last three fiscal years
The records are unduplicated using four variables: Patient number, sex, community of residence, and date of birth		Population is assigned to a Service Unit within the community of residence
The records with the latest date of service are selected		
The diabetes case is assigned a Service Unit within the patient's community of residence		

Approximately 40 Service Units (i.e., 11% of the IHS service population and 7% of the IHS user population) are excluded from the prevalence calculations because of incomplete data, low population or patient counts, large relative difference when compared to chart audit patient count, or as recommended by the IHS Area Diabetes Consultants.

Results

The rates of increase in diabetes prevalence are based on two-point estimates. These two-point estimates do not reflect the fluctuations in prevalence within a specific time interval. The rates of increase are also relative measures. For example, a small absolute increase on a low baseline estimate will have a relatively greater percent increase when compared with a larger absolute increase on a higher baseline estimate.

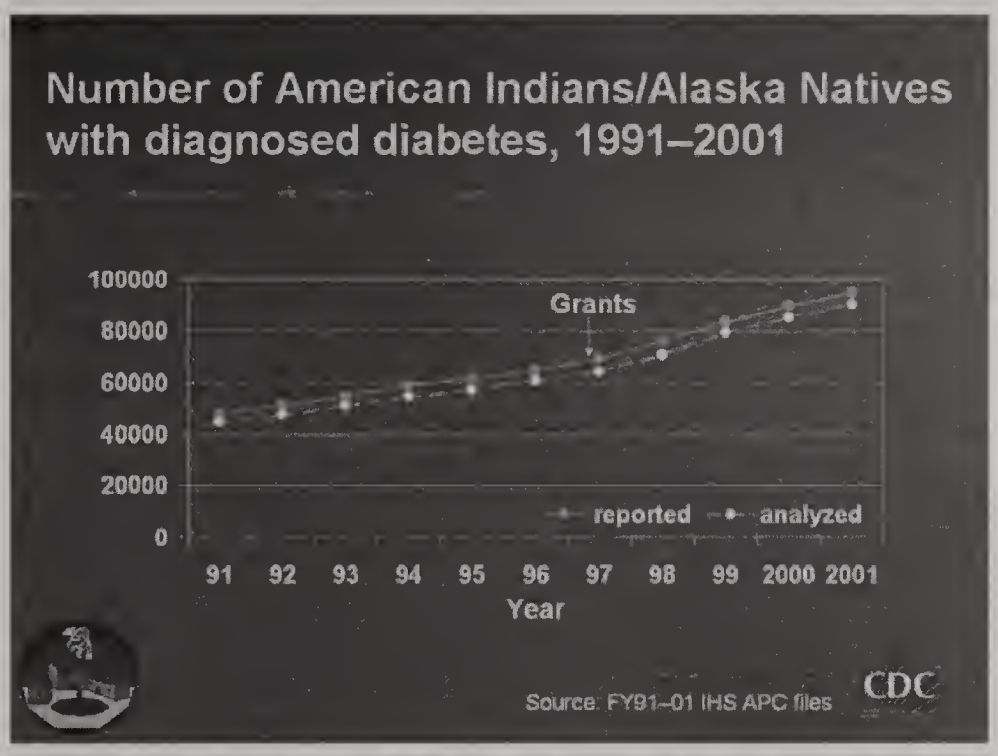

Figure 1. Number of AI/ANs with diagnosed diabetes, 1991–2001

Figure 1 shows the number of AI/ANs with diagnosed diabetes, which has increased from approximately 50,000 in 1991 to nearly 100,000 in 2001. The slope in the number of cases reported becomes steeper in 1997, the year that the *Special Diabetes Program for Indians* was implemented. This trend is also occurring in the general U.S. population.

Figure 2. Prevalence of diagnosed diabetes among AI/ANs, 1997–2001

Figure 2 displays the diagnosed diabetes prevalence estimates for the last five years since the *Special Diabetes Program for Indians* was implemented. For all AI/ANs, diabetes prevalence has increased from 5.4% in 1997 to 6.9% in 2001. Among adults who are 20 years and older, the prevalence increased at the same rate, from 9.5% in 1997 to 12% in 2001.

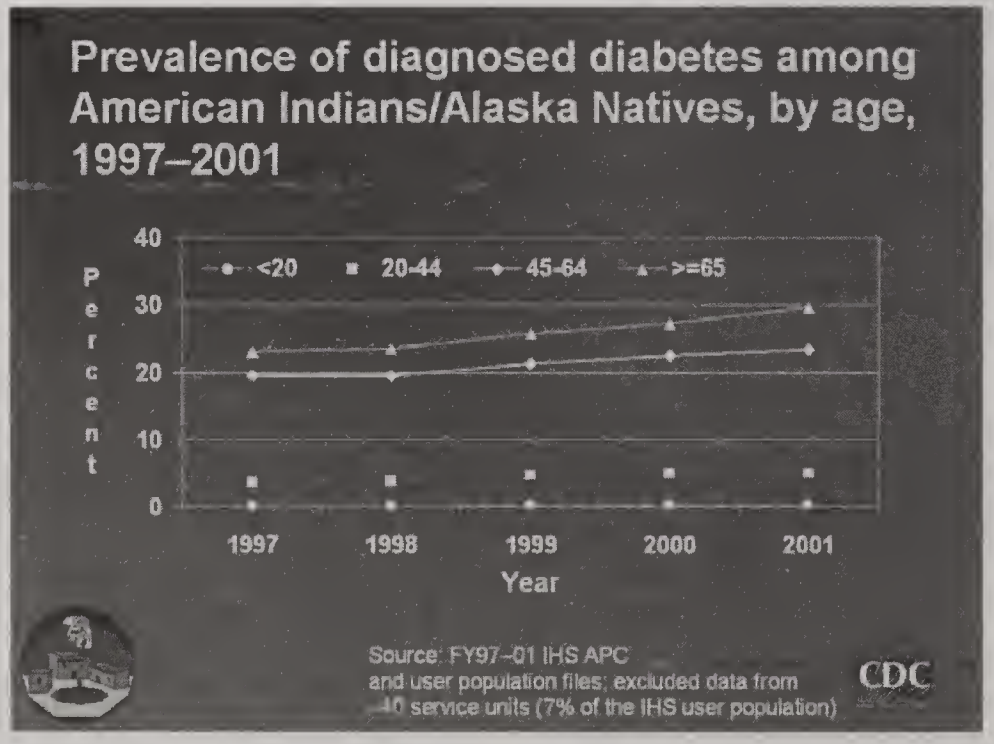

Figure 3. Prevalence of diagnosed diabetes among AI/ANs by age, 1997–2001

Figure 3 displays the diagnosed diabetes prevalence estimates by age since 1997. Diabetes prevalence increased in all age groups, increasing with age from those who are 20 years to those who are 65 years and older. Among AI/ANs who are younger than 20 years, diabetes prevalence increased 39%. Among adults aged 20–44 years, it increased 38% from 1997 to 2001. Among adults aged 45–64 years, prevalence increased 20% from 1997 to 2001. For AI/ANs who are aged 65 years and older, prevalence increased 28% from 1997 to 2001. In 2001, one in three AI/ANs aged 65 years and older had diagnosed diabetes.

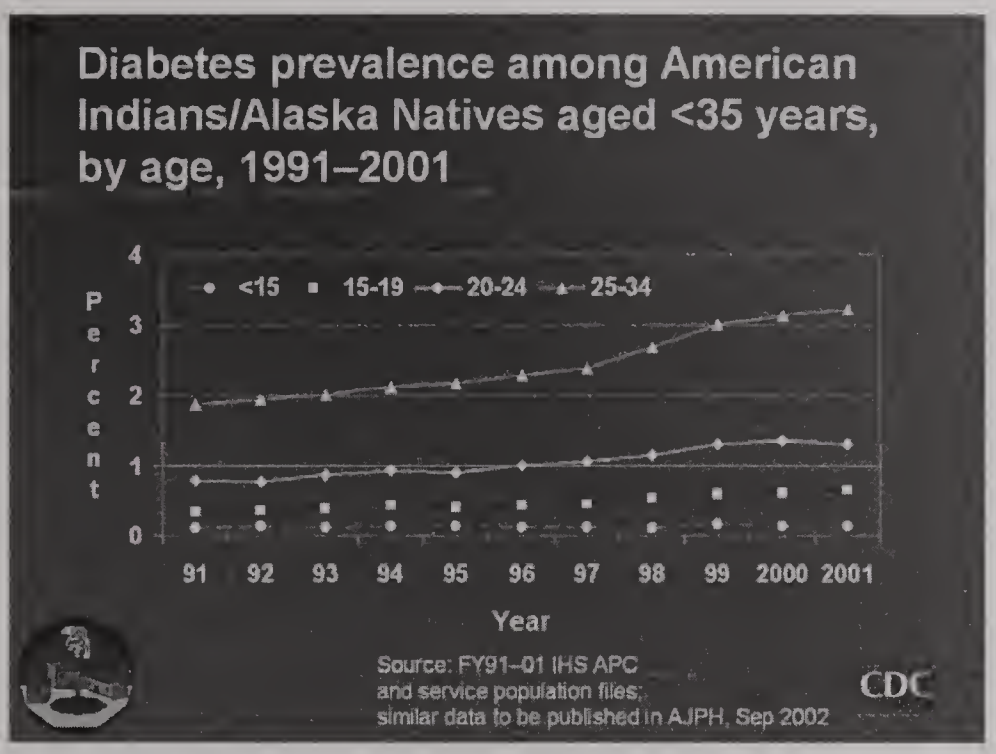

Figure 4. Prevalence of diagnosed diabetes among AI/AN age 35 years old and younger, 1991–2001

Figure 4 displays the increase in diabetes prevalence among the younger age groups. The increase in prevalence ranges between 66% and 90% since 1991 with the exception of those younger than 15 years.

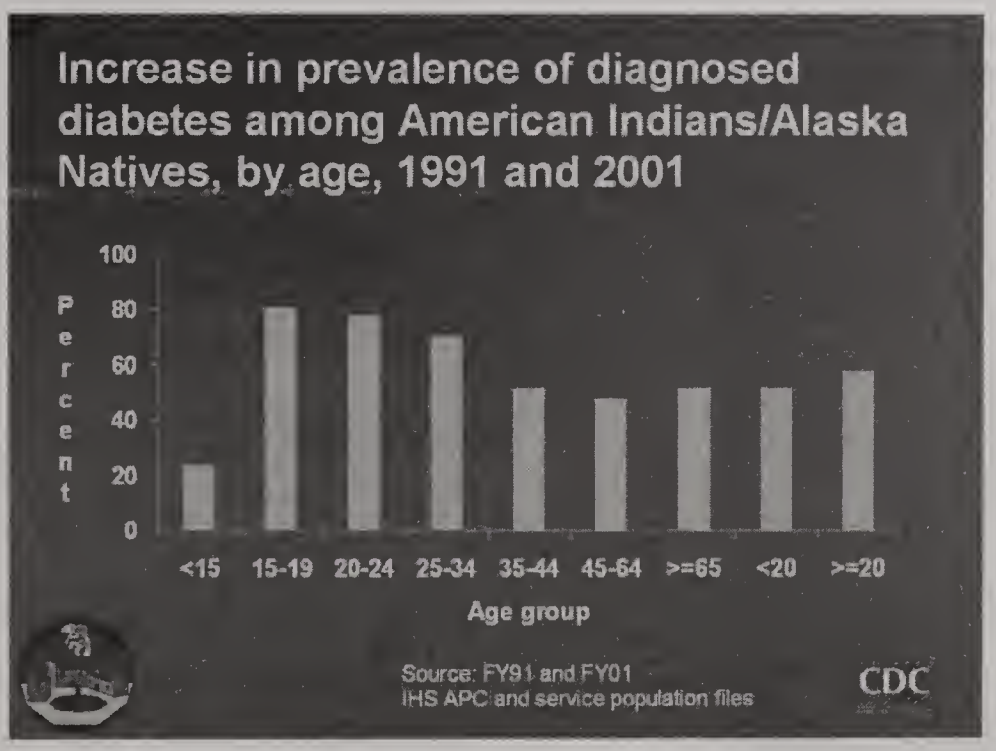

Figure 5. Increase in prevalence of diagnosed diabetes among AI/ANs by age, 1991 and 2001

As Figure 5 displays, the highest increase in prevalence has occurred among adolescents aged 15–19 years, with an 80% increase since 1991. In the general U.S. population, the highest rate of increase has occurred in adults aged 30–39 years.

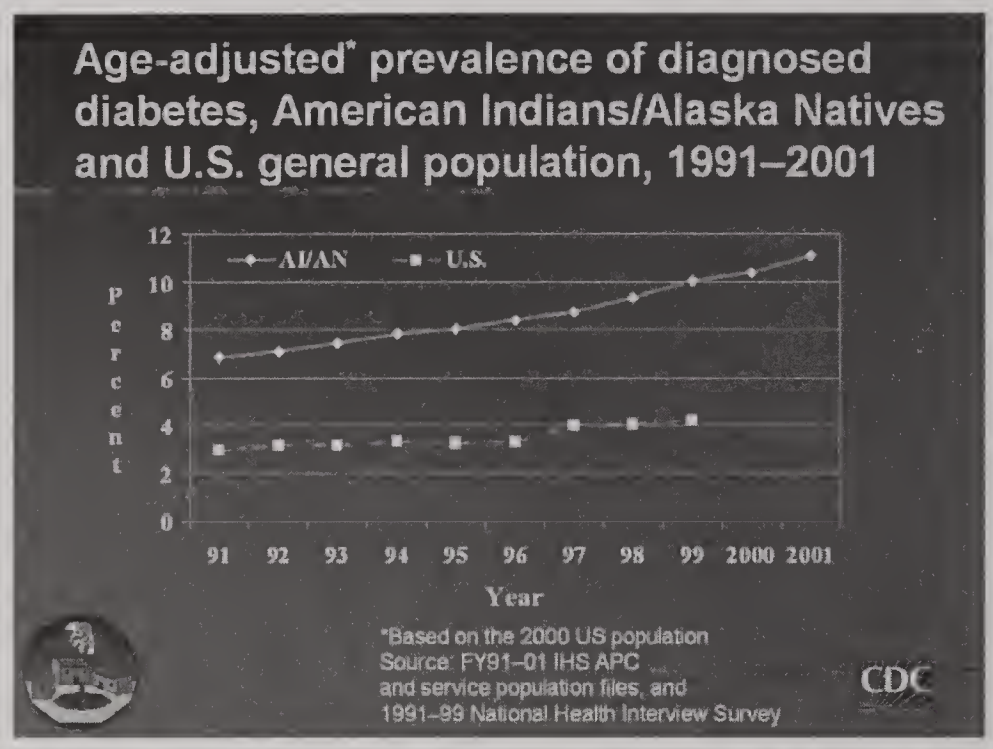

Figure 6. Increase in prevalence of diagnosed diabetes among AI/ANs and the U.S. general population, 1991–2001

Figure 6 displays how the prevalence of diagnosed diabetes in AI/ANs compared to the U.S. population. While the diabetes prevalence has increased for both AI/ANs and the U.S. general population, the gap in diabetes prevalence between the two populations is widening. Among AI/ANs, diabetes prevalence has increased from 7% in 1991 to 11% in 2001, whereas it increased from 3% to 4% in the general U.S. population. This data indicates that a large disproportion of diabetes exists among AI/ANs when compared to the general U.S. population, and the burden of diabetes is increasing for AI/AN communities.

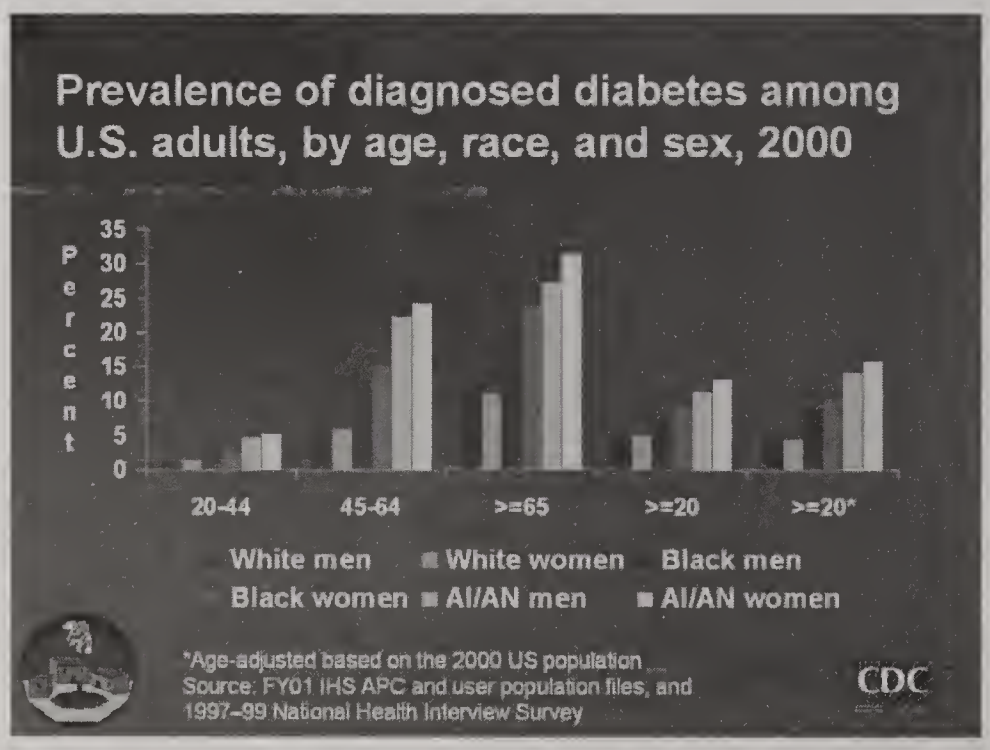

Figure 7. Prevalence of diagnosed diabetes among U.S. adults, by age, race, and sex, 2000

Figure 7 shows that AI/ANs experience the highest burden of diabetes among U.S. adults across all age, race, and sex groups. Furthermore, the highest prevalence rates for diabetes are seen in AI/AN women across all age groups, and the largest difference in prevalence was seen between AI/AN and non-Hispanic whites younger than 65 years (3.6 times).

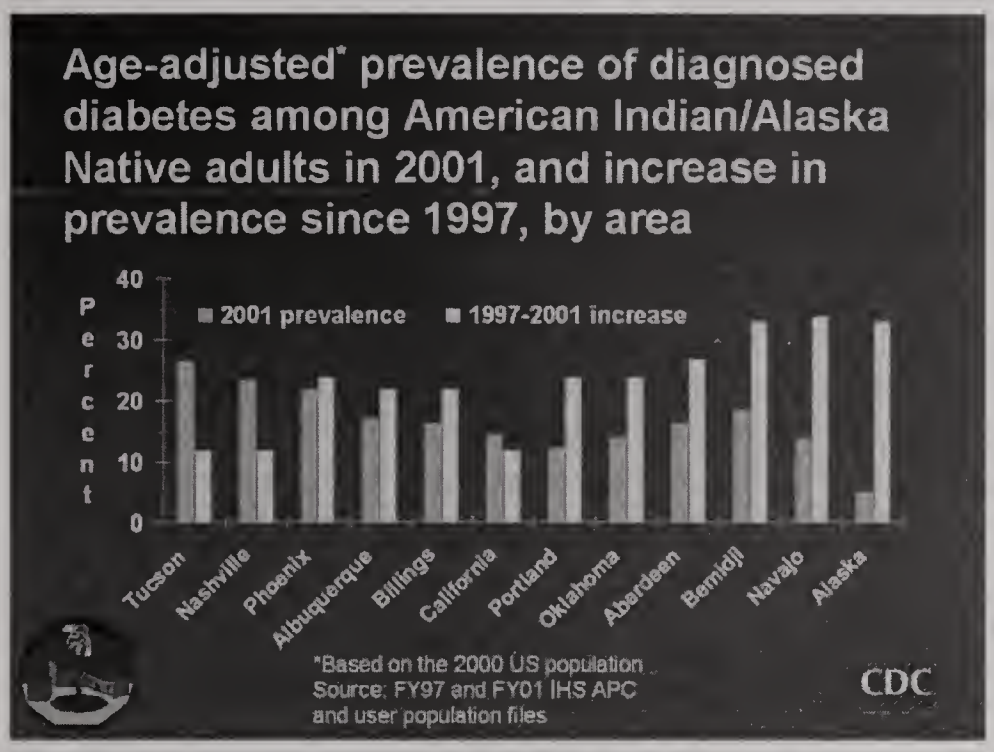

Figure 8. Prevalence of diagnosed diabetes among AI/ANs in 2001; increase in prevalence since 1997, by Area

Figure 8 displays the prevalence of diagnosed diabetes in 2001 and the increase in prevalence since 1997 by IHS Administrative Area. Three IHS Areas—Tucson, Nashville, and Phoenix—have an age-adjusted diabetes prevalence among adults between 20% and 30%. All other Areas, with the exception of Alaska, range between 10% and 15%; Alaska has the lowest age-adjusted prevalence at 5%. For all IHS Areas, the prevalence is 15%. Three IHS Areas—Bemidji, Navajo, and Alaska—experienced an increase in prevalence of over 30% since 1997. The Tucson, Nashville, and California Areas experienced the lowest increases at just slightly above 10% since 1977. The remaining IHS Areas experienced increases between 20% and 30%. For all IHS Areas, the increase in the prevalence of diagnosed diabetes is approximately 25%.

Uses for IHS diabetes data

The data that are collected and analyzed by the IHS National Diabetes Program are published in various IHS reports, used to monitor progress toward achieving Government Performance and Results Act (GPRA) objectives, used to help direct IHS Area fund allocations, presented at Tribal Leaders Diabetes Committee meetings, and presented in briefings to Senate committees. The data are also disseminated through various means:

- IHS Area Diabetes Consultants
- IHS National Diabetes Program website
- Congressional reports
- CDC National Diabetes Fact Sheet
- Healthy People 2010
- Conferences
- Journal articles, such as those published in the *Morbidity and Mortality Weekly Report*, *Diabetes Care*, and *American Journal of Public Health*

Plenary Session

Current Issues in Health Disparities Common in American Indian Communities

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Purpose

To discuss health disparities in American Indian and Alaska Native (AI/AN) communities—in particular our current knowledge about health disparities affecting American Indians, the national initiatives that are addressing health disparities, and areas of need related to health disparities.

What do we know about health disparities in AI/AN communities?

Health disparities in AI/AN communities have a long history. During pre-contact, before European nations came to North America, AI/ANs had their own system of medicine, cultural practices, and public health practices. Although health disparities did exist during pre-contact—perhaps one tribe had more traditional healers or better access to medicinal herbs than another tribe—those disparities were not considered a horrible injustice. We are concerned about health disparities today because of the history of AI/AN health and because these disparities are a result of social injustices or unfair events that happened in our past.

Our awareness of disparities as a negative issue began in the early 1800s when the War Department became involved in helping American Indians deal with the epidemics that they were facing. The federal government recognized that American Indians were dying at disproportionate rates because they did not have the immunity to deal with the diseases that had been brought to this country. In the mid-1800s, as more and more tribes were signing treaties, the treaties began to include stipulations related to the provision of health care. Responsibility for health care was transferred from the War Department to the Bureau of Indian Affairs, which was responsible for Indian issues at that time.

Many public health policies, administrative decisions, and political decisions have resulted in health disparities for AI/ANs. Probably the worst example is the Dawes Act of the 1880s, which allowed the federal government to break up reservations into allotments of land, designate males as the heads of households despite the fact that some tribes had a matrilineal culture, and make traditional practices illegal. The Dawes Act is an important lesson because its effect was the destruction of Indian culture, which resulted in a significant decline in the health status of American Indians. Many of the social problems that we face today relate to this history of children being taken away from their families to go to boarding schools and the loss of some traditional practices. Traditions are what keep our communities healthy, and to make them illegal was destructive to the health and well-being of Indian communities.

By the early 1900s, the health status of American Indians was declining rapidly, and people began to recognize the existence of significant disparities in the health status of American Indians. The Merriam Report, published in the 1920s, was one of the first reports that formally documented these significant health disparities. In 1921, Congress passed the Snyder Act, which authorized Congress to provide funds for the "conservation of health" in American Indian communities.

Although the Snyder Act provided extra funding and healthcare facilities for American Indian health, by the mid-1900s, the health status of American Indians continued to lag behind the general population. In recognition of this, the Indian Health Service (IHS) was established in 1955 with the mission of raising the health of AI/ANs to the highest possible level. The IHS is a comprehensive primary health care system on or near reservations that includes hospitals and clinics, and it represents the federal trust responsibility to provide health care for AI/ANs that is well-documented through an accumulation of laws, treaties, and Supreme Court Decisions. Over time, the IHS made dramatic improvements in the health status of AI/ANs, but disparities continue to exist, which are well-documented in *Trends in Indian Health.*

The language used in the Snyder Act, the mission of the IHS, and other Indian health policies are not specific, and they force us to ask some questions about our goals for AI/AN health:

- Do we need to aim higher than eliminating health disparities? Should we refuse to settle for equalizing our health status with that of other groups?
- What is the "conservation of health"? Does it mean that we eliminate health disparities? Does it mean that we make health the best that it can be?
- Is the elimination of health disparities as far as we want to go?
- What is the federal government supposed to provide?

Where do health disparities in AI/AN communities exist?

Data and research support the existence of health disparities for the usual public health indicators, such as infant mortality, prevalence of diabetes, prevalence of cardiovascular disease, or cancer mortality. However, we face the desperate need to address disparities that exist in many other areas, such as the socioeconomic disparities that are prevalent in AI/AN communities that have a tremendous effect on health. We suffer from among the lowest income rates, highest unemployment rates, and lowest educational levels. Tribal leaders often focus on the economy, jobs, casinos, and businesses, placing a lower priority on health care. In fact, healthcare often ranks fifth or sixth on the list of priorities for many tribes. However, socioeconomic status has an important role in improving health. If you have a community that has a strong economy, good social support, and jobs, you also have a higher level of health status.

Other health disparities relate to access to care and availability of resources. We often lump AI/ANs into one group, but access to care issues vary among communities. For example, some of you work at large hospitals and have specialists on site, while some of you work at small clinics with one doctor. Some clinics have podiatrists, so their foot care is better. Other clinics have ophthalmologists, so their level of eye exams is better. We are not on a level playing field

within our own healthcare system. How much longer can we allow these disparities within our system to affect the quality of healthcare?

What is new with health disparities in AI/AN communities?

In recent years, the government has launched a number of initiatives aimed at eliminating racial and ethnic health disparities:

- Department of Health and Human Services (DHHS) Initiative to Eliminate Racial and Ethnic Disparities in Health for diabetes, cardiovascular disease, infant mortality, HIV/AIDS, cancer, and the treatment and management of immunizations (1998)

- Health People 2000 and 2010

- Centers for Disease Control and Prevention (CDC) Racial and Ethnic Approaches to Community Health (REACH) Initiative (1999)

- National Institutes of Health (NIH) Center for Minority Health and Health Disparities (2000)

- DHHS Advisory Committee on Minority Health

In 2002, the Institute of Medicine (IOM), a non-profit organization responsible for generating reports for Congress on various health issues, released its report on racial and ethnic health disparities, titled, "Unequal Treatment Confronting Racial and Ethnic Disparities in Health Care." In the late 1990s, Congress directed the IOM to study the extent of racial and ethnic differences in health care *not* due to access to care issues. (We already know that if you have differential access or if you do not have insurance, you are more likely to have a lower level of health.) In addition, Congress directed the IOM to identify the sources of these disparities and make recommendations for interventions to eliminate health care disparities. The report detailed the following major findings:

- Finding #1: Significant disparities in the health of racial and ethnic minorities exist and cannot be accounted for based on differences in access and socioeconomic factors. Because these disparities are associated with worse outcomes in many cases, the disparities are unacceptable.

- Finding #2: Racial and ethnic disparities in health care occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.

- Finding #3: Many sources—including health systems, healthcare providers, patients, and utilization managers—may contribute to racial and ethnic disparities in healthcare.

- Finding #4: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in health care. While indirect evidence from several lines of research supports this statement, a greater

understanding of the prevalence and influence of these processes is needed and should be sought through research.

The general recommendation of the IOM report was to increase awareness in the general public, stakeholders, and health care providers. Other recommendations included reducing barriers to access, cross-cultural education for providers, patient education and empowerment, and addressing data collection, monitoring, and research needs. In addition, several key issues emerged in the report:

- *Elimination* of health disparities—not *reduction* of health disparities
- *Intervention* (e.g., developing and measuring the most effective ways of eliminating disparities)—not *observation*
- *Measuring* progress—not *observing* progress
- *Education* and *awareness* of disparities—not *denial* that disparities exist

Within the framework of health disparities, diabetes is hot issue. As a result of the research that has documented the problem and the effectiveness of interventions, efforts to combat diabetes have significant political support. The prominence of diabetes in AI/AN health over the last 20–30 years has led to a large infusion of money to develop community-based programs that other minorities have not had.

What are the areas of need?

Although AI/AN communities benefit from a wonderful healthcare system, resources, and committed providers, we still have a long way to go. We need to focus more on the following areas:

- Gathering more data on health disparities
  - *Surveillance* is needed to document trends over time. Collecting and analyzing data on the local level is important for program planning. Data should be used to *show progress,* not just to document problems.
  - *Measuring the quality of care* should not just include clinical care, but be expanded to include access to care (e.g. Are people going to your new program? If not, why are they not going?) and patient satisfaction (e.g. Are people satisfied with the new diabetes grant programs that you have implemented as a result of the *Special Diabetes Program for Indians*?).
  - *Evaluation* of the effectiveness of programs and interventions is needed—observation is no longer enough.
- Implementing more effective strategies to address health disparities

  - A *public health approach* is needed. This focuses on communities, not just individuals. We must recognize that diabetes is a result of both individual and community factors.
  - Entering into *new partnerships* is needed. This includes providers, patients, clinics, and tribal and community leaders.
  - Providers need to consider *new roles* in healthcare. They should think of themselves as *resources*, not experts.
  - A *broader framework* is needed. For example, focus on community wellness, not just a disease like diabetes. A broader framework can address many more diseases at once, such as chronic diseases.

- Creating a new definition of goals
  - Is the *elimination* of health disparities enough? Diabetes audits show that 50% of AI/ANs receive foot exams and this is on par with the rest of the U.S., but is that enough? Should we push even further and get to the highest possible level—to 100%?
  - Who defines *success*? How much of a role does the community have in defining success? How do definitions from the community differ from that of patients or providers? Have you had community meetings to define what a successful diabetes program is? Tribal consultation should occur at all levels, not just the federal and state levels.

- Providing more effective education on health disparities
  - *Education* should be provided for tribal leadership, health providers, patients, Congress, and the Administration. We should also build local capacity to conduct research (e.g. the Native Research Centers for Health (NARCH) initiative).

- Recognizing the unique status of tribes
  - Although AI/ANs are underrepresented, we are *not* just a minority group. Tribes have a special status as sovereign nations and a government-to-government relationship with the federal government. The federal government has a trust responsibility to provide healthcare to American Indians.

In summary, health disparities do exist and have been around for a long time. However, the recent emphasis on the elimination of health disparities is still not enough. What is needed? More data, new strategies, and new goals are needed. Your presence at this conference and your contributions are extremely important in terms of documenting the needs of your communities, documenting the quality of care that you are providing, and demonstrating that we can work together to win the fight against diabetes.

Plenary Session

Important Issues in Diabetes for Public Health

Frank Vinicor, MD
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Centers for Disease Control and Prevention

Purpose

To provide an overview of five important diabetes issues and describe the differences between clinical medicine and public health.

Issue #1: Diabetes is disabling, it is deadly, and it is getting worse

Diabetes is a serious, widespread, and costly chronic disease, affecting 17 million individuals in the U.S. and millions of families and communities. In one 24-hour period, 2,700 people will be diagnosed with diabetes, 220 people will have an amputation, 110 people will enter an end-stage renal disease program, 90 people will go blind, and 240 people will die from diabetes.

Between 1990 and 1998, diabetes prevalence among adults increased 33% in the U.S., growing fastest among adults aged 30–39 years. Alarmingly, type 2 diabetes, an illness once thought to afflict only adults, is now found in children and adolescents. Because these children have acquired type 2 diabetes at such a young age, they will experience more years of disease burden and a higher probability of developing serious diabetes-related complications—complications that will threaten their life expectancy, reduce their quality of life, and lower their productivity during the prime years of their lives.

The Centers for Disease Control and Prevention (CDC) estimate that the number of Americans with diagnosed diabetes will increase from 11 million to 30 million between 2000 and 2050. Nearly all studies indicate that the cost of diabetes to a system, such as the Indian Health Service (IHS) or Medicare, will be roughly three times the prevalence. The formula for this concept is $C = 3P$, where C equals cost and P equals prevalence. For example, if the prevalence of diabetes in the Medicare group is 10%, that 10% will consume 30% of all the resources in Medicare. With the number of people who have diabetes expected to triple in less than 50 years, how will our health systems cope?

Issue #2: Our choices for action for today and tomorrow

To improve clinical care, we can no longer focus only on the individual. To illustrate, let us examine the amount of time that individuals and health care providers spend with one another. In a three-month period of time, there are 129,600 minutes. Providers would generally be pleased if our patients could see us for 30 minutes every three months. That amounts to 0.02% of an individual's time spent with a health care provider. Can we really make an impact after spending only 0.02% of a person's time with them? The answer is most likely no. I therefore suggest that focusing on an individual is not going to improve care. Although it is important to focus on the individual, we are still missing an incredible opportunity to help people with

diabetes or other chronic diseases. We have incredible amounts of knowledge, an incredible amount of need, and a huge gap in between. Beyond the individual is the system of care and the environment—not in place of the individual, but where the individual lives, works, and plays.

Issue #3: Challenges associated with our choices

Even if we focus on the individual and the system, are we trying to beat a dead horse to life? How do we deal with the huge gap between the individual and the system? A challenge for all of us is to collect information about our system, build a bridge between the two, and use the bridge to transfer the knowledge where it is needed.

Issue #4: Even if we improve or have perfect care, that alone is not going to cut it

We could do the best job and have the best system, but these things alone are not going to cut it for two reasons. First, behaviors, not genes, are changing. For example, research shows that less people walk to work or school. Second, because genetic changes are not responsible for the diabetes epidemic (i.e., it takes more than a decade to see enough changes in our DNA to blame genetics for an explosion in the prevalence of diabetes), we cannot rely on pharmaceutical companies to come up with a "magic pill" to fix diabetes—certainly not in the near future.

Issue #5: The *new* and *exciting* challenges that face us into the future

We need to address primary prevention. Through primary prevention, we will realize that diabetes cannot paralyze us. Without primary prevention, however, we will be overwhelmed. The Diabetes Prevention Program, which showed that people with prediabetes (i.e., impaired glucose tolerance), including American Indians and Alaska Natives, can reduce their risk of developing diabetes by 58% by making moderate, positive changes in their diet and physical activity level. The Diabetes Prevention Program further showed that people with prediabetes who took metformin reduced their risk of developing diabetes by 31%.

Primary prevention requires that we identify who we want to target. As we broaden our scope to include more and more people in our primary prevention efforts, the number of people for whom we have responsibility increases dramatically. At the very least, people with prediabetes should be the target. With at least 16 million people in the U.S. who have prediabetes, our target population is not a small number. Following people with prediabetes, we should target people who are overweight. In addition, should we target people with Syndrome X or Insulin Resistance Syndrome? Roughly 40 million people in the U.S. have Insulin Resistance Syndrome, and most people with type 2 diabetes come out of this group.

We face a number of significant challenges when we address primary prevention:

- How do people feel about primary prevention? People's reactions, feelings, and backgrounds are important.
- How will we pay for a primary prevention program that targets so many people?
- How will we staff our primary prevention programs? In the Diabetes Prevention Program, one Certified Diabetes Educator, nurse, or dietitian took care of 20 people. We would need an additional 800,000 Certified Diabetes Educators, nurses, or dietitians to care for the 16 million people with prediabetes.

What is public health anyway?

Although clinical medicine and public health complement each other, they also view the world in very different ways. The target of clinical medicine is the individual or the person, whereas the target of public health is the environment or the place. In the clinic, the patient John Jones is assumed to have the power to do everything right if he would only listen to the providers. In public health, John Jones lives in an environment, which has a strong influence on what he does. Is it the person or the place that will help John Jones prevent diabetes or care for it properly? Beyond John Jones, the clinical world is concerned about who comes into the clinic. On the other hand, public health is concerned with who does not come into the clinic.

The differences between clinical medicine and public health can also be seen when looking at the six step process to develop a program aimed at improving health:

- Step one: Carry out fundamental research to see if a particular program would be *possible*.
- Step two: Conduct efficacy studies, like the Diabetes Prevention Program, to see if the program *works* in an ideal setting.
- Step three: See if the program would work in the real world with limited resources.
- Step four: If the program works in the real world, determine the cost of the program in terms of both money and time.
- Step five: If the program works at a reasonable cost, determine if you can make it available through supportive policies.
- Step six: If it is possible to make it available, determine if it is possible to make the program available to everybody.

Clinical medicine focuses on the first two steps, but public health focuses on the last four steps. These last four steps need the most attention: A program does not matter if it works only in an ideal world. If it is not accessible to all people, it does not mean anything.

A third example of the differences between clinical medicine and public health can be illustrated through the following example. Imagine that we have a single house of health in the U.S. This house has dimensions: It has height, which represents how much we know, and it has width, which represents how many people can fit into the house. Thus far, our country has made its major investment in raising the roof on this house of health. For example, we have better CT scans, better mammographic images, the human genome project, and improved insulin. Although these have resulted in tremendous benefits, our country should make another investment in repairing this house. We should invest in widening the floor—making sure that more people have access to what we already know. Clinical medicine is more interested in raising the roof—having the best, newest, and most expensive medicine. Public health, on the other hand, is more interested in providing all people with access to good, albeit not perfect, resources. Public health says that everybody should have access to a *simple* ACE inhibitor; public health does not say that it needs a *better* ACE inhibitor.

A final difference between clinical medicine and public health is that clinical medicine generally thinks horizontally, whereas public health generally thinks vertically. For example, in clinical medicine, a provider who has a patient with coronary heart disease will think horizontally and ask, "What are his lipids, blood pressure, homocystein levels, and tobacco use?" In public health, the provider will think vertically and say, "I want to know this patient's physiologic influences, but I am also interested in his or her physical activity level, psychosocial factors, where he or she lives, and his or her social class, gender, race, ethnicity, and cultural issues." For two reasons we need to incorporate a vertical view. First, we need to realize that health cannot be isolated; other factors influence health. Emerging from this is the concept of social capital, the collection of associations, relationships, and bonds that influence the strength and health of communities. Second, we need to accept that there are much more powerful influences on what John Jones does than the advice of physicians.

Data give you power and responsibility

Data and information give you power not only to help the individual, but also to make a difference for a community. Data can help you determine how to redesign your system so more people can benefit. Because so much of what happens to our patients happens outside of the clinic, providers need to add another dimension to their responsibilities: Providers need to be better citizens and participate in the community to understand the qualitative issues that affect the community's health. Collect data and information wherever you go, make it colorful, and make it simple to understand.

Is diabetes a public health problem?

Diabetes is a big problem, and it is going to get bigger before it gets smaller. We can influence this trend in two ways. First, we can influence how big diabetes gets before it gets smaller. Second, we can influence how long diabetes stays big by improving care through primary prevention and by becoming more active in our communities.

But, is diabetes a public health problem? Dr. Thomas Parren Jr., Surgeon General from 1936 to 1948, defined a public health problem as whenever a disease is so wide-spread in a population, so serious in its effects, and so costly in its treatment, that the individual unaided cannot cope with it. I think diabetes qualifies. To address the public health problem of diabetes effectively, we need to move beyond clinical medicine to where people live, work, and play.

Plenary Session

Using Diabetes Data to Improve Clinical Care

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Health Partners Research Foundation

Clinical Associate Professor
University of Minnesota

Purpose
To describe a road map that uses diabetes health data to improve clinical practice.

Health data and information systems support
To improve clinical care for patients living with diabetes, you need health data and information systems support. This involves several steps. First, identify the people who have diabetes. Second, reach a consensus for the goals on which your diabetes care team will focus (e.g., choose an evidence-based goal, such as glucose, lipid, or blood pressure control; tobacco cessation; aspirin use; eye, foot, or nephropathy exams). Third, organize an effective, high functioning care team that includes not only doctors, but also nurses, educators, pharmacists, community representatives, and the patients themselves. Fourth, activate your patients.

Step #1: Identify who has diabetes
The first step toward improving diabetes care is to identify the people who have diabetes. This involves developing an accurate diabetes registry or list of patients who have diabetes by using diagnostic codes, identifying patients who fill prescriptions for diabetes-specific medications (e.g., insulins, sulphonylureas, TZDs, or metformin), or using laboratory test data (e.g., patients who have A1c > 6.5%).

Tradeoffs always exist between the sensitivity of diabetes identification (i.e., the fraction of all those with diabetes you were able to identify) and the positive predictive value of the identification method (i.e., out of those you identify, the proportion who actually have diabetes). In general, if improvement strategies are going to be rolled out to patients or physicians, it is better to have a high positive predictive value, so you do not lose credibility with doctors or anger patients because the patients targeted for improvement did not actually have diabetes.

The main point is to move forward. The perfect is the enemy of the good: Patients and physicians will forgive imperfect data if it is substantially accurate and if their expectations for perfect data have been tempered with more realistic expectations.

Step #2: Decide what you want to monitor
Once you identify who has diabetes, you need to decide what you want to monitor. The list of potential variables to monitor is very long, so the best strategy is to decide on one or two

variables, rather than trying to monitor everything at once. Once you develop momentum, you can add to your list of variables. It is preferable to start with variables related to the prevention of diabetes complications, such as glucose, blood pressure, and lipid control. If you are able to better manage those variables, you are likely to see less eye, foot, and kidney complications. By starting with prevention, you will be able to fix the underlying causes of the complications. It is more difficult to improve glucose or blood pressure control than it is to collect urine samples, but you will see improved results over five or ten years if you focus on strategies that address the root causes of complications.

Step #3: Prioritize patients

Determine how you will prioritize your patients. Not all patients are equal: Some are in worse control or at higher risk than others, some respond better to certain situations than others, and some are more willing to improve their health than others. By prioritizing patients, you can tailor clinical care to maximize its effectiveness and efficiency. At least two approaches may be applied to prioritize patients. One approach is to prioritize patients based on their risk of complications or adverse health events. Another strategy is to prioritize patients based on their readiness to change—their readiness to engage in activities to improve self-care or increase the intensity of diabetes care.

One strategy is to prioritize patients based on their willingness to change and focus your attention and resources on those patients. In the past, the provider or diabetes educator would spend time with an unwilling patient until they *could be made* willing to change. A more productive method is to deliver a message to the unwilling patient that is tailored to their readiness to change, and then revisit them at a future point in time. An example of a message for the unwilling patient is, "I understand that you are not ready. That is okay. If you were able to _____ (choose one: stop smoking, improve your blood pressure control, improve your overall diabetes care, etc.), you would benefit by _____ (choose one: reducing your risk of blindness, living longer to see your grandchildren grow up, avoiding a stroke, etc.). You are not ready now, but I'd like to call you again in six months, if that is okay with you." Do not spend all of your time and resources trying to get a patient to change. Instead, find patients who are ready to change. You will get a lot further with those patients.

Another strategy is to prioritize patients based on risk. Keep in mind that prioritizing patients based on risk and a willingness to change will not result in the same list of patients. An example of a patient who would be a high priority based on risk is a person with diabetes who has an A1c over 9%, systolic blood pressure over 140 mm Hg, or LDL-cholesterol over 130 mg/dl—especially if they already have cardiovascular disease. This is a person who is at high risk for developing serious complications and should receive prompt attention. A second example is a person who has not had any tests, so you do not know what their glucose or cholesterol control is. You should make it a high priority to get this patient in for testing to determine their risk for developing diabetes or adverse health events.

Step #4: Active outreach

Once you have found the patients who have diabetes, monitored something that is important, and prioritized your patients, you will need to do active outreach. Although data can be used to help streamline this process and make it more efficient, you will need to reorganize your clinic to

improve chronic disease care, determine staff roles and responsibilities, and obtain buy-in on your active outreach strategy from all members of the team. Many clinics, including ours at HealthPartners, have had the most success when active outreach activities were assigned to members of the diabetes care team, such as nurses who have an interest in diabetes, and not to physicians.

Active outreach has some hazards. If your diabetes care team thinks that a person who has not been seen in awhile has diabetes, providers need to be careful about what they say to the person. Because diabetes can be a stigmatizing disease, people with or at-risk for diabetes are in various stages of denial. When you do active outreach, you should have your communication with patients carefully scripted. For example, we make telephone calls to patients to assess their readiness to change. The nurse will say to the patient, "Dr. O'Connor and I were thinking about you and wondering why we have not seen you in awhile with respect to your diabetes. The last time we saw you, there were some things that we wanted to work on with you; are you ready to do that?" If the person says, "No, I am not," then the nurse responds, "That is fine. We will talk to you again later." If the patient instead says yes, then the nurse schedules a visit.

Step #5: Visit planning

Another important improvement strategy is visit planning. In a typical visit planning scenario, immediately before a physician sees a patient, the physician pulls the chart, flips through the last couple of notes, and walks into the exam room to see the patient. In less than a minute, the physician needs to determine the reason for the patient's visit. Acute problems, such as chest pain, broken bones, and bleeding, will rise quickly to the top of the physician's attention list, resulting in neglect for chronic problems like diabetes.

A better visit planning scenario would involve a nurse flagging the chart so that the physician knows that the patient has a chronic condition, like diabetes. The flag might also contain brief notes on the patient's A1c, blood pressure, and lipid levels, and whether the patient is taking metformin or aspirin. This information presented in a quick, concise way would enable the physician to provide better care for the patient by focusing time and attention on issues that may confer long-term clinical benefit. Otherwise, it is very unlikely that the physician would know about the A1c level, lipid level, and medications.

One problem with this form of visit planning is that it is very time-consuming and expensive, and it can disrupt other clinic activity. An enhancement might be to automate visit planning, but this is a challenge that remains to be solved. In the future, electronic medical record systems, or other creative uses of automated database information, may lead to automated visit planning.

Data enhancements

Basic diagnostic, laboratory, and pharmacy data can help improve diabetes care. But, if you are already using these data effectively, what additional data would be useful for improving diabetes care? The following are examples of data enhancements that can help improve care:

- Patient reported data, such as behavioral information (e.g., tobacco use and physical activity), willingness to change, height and weight, and routine aspirin use
- Co-morbidity measures (e.g., does the person have heart disease?)

- Continuity of care measures (e.g., patients who jump from one doctor to another generally do not have as good diabetes care as patients who see the same doctor)
- Medical adherence measures from pharmacy data
- Automatic capture of blood pressure data, especially systolic blood pressure, to assist in prioritizing patients by risk

Issues related to data

When using data to improve clinical care for diabetes, you should keep several issues in mind. First, state and federal laws dictate that data must be maintained with sensitivity, respect, and confidentiality. Build assurances into your system to protect privacy and minimize breach of confidentiality. Second, do not wait for a magic fix-it, such as improved technology, to improve clinical care. We must work *continuously* to improve diabetes care. For example, two papers in *Diabetes Care*, one from the Mayo Clinic and one from Massachusetts General Hospital, showed that electronic medical records resulted in higher levels of glucose and lipid testing. However, the technology did not result in better values for those tests, which is the real goal. The lesson from this research is not to postpone activity while you are waiting for a new technology. Our challenge is to work with the data that we have and to do the most that we can with it now, rather than delay and pin our hopes on future technology. Third, always remember to be both innovative and practical, and take it one step at a time.

Plenary Session

Lessons Learned from the Diabetes Management System and Other Systems in Indian Health Service

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Phoenix Indian Medical Center

Purpose

Using real-life experiences, provide answers and insights to the Diabetes Management System of the Indian Health Service (IHS): 1) why is the logic used in the IHS Diabetes Care and Outcomes Audit (diabetes audit) slightly different than that used in the diabetes supplement; 2) did we show an improvement in diabetes care or did we only change the definitions; and 3) why do we continue to encounter data problems?

Overview of diabetes data from the Resource and Patient Management System (RPMS)

Beginning in the late 1980s and continuing to this day, the IHS has had an interest in capturing diabetes-related data from RPMS. The following are some key steps in this process:

- In the late 1980s and early 1990s, Dorothy Gohdes and Steve Helgerson began using RPMS data to obtain diabetes prevalence numbers for different Service Unit populations.
- By 1992–1993, the IHS developed a case management system that could develop a diabetes registry within RPMS.
- In 1996, the first RPMS diabetes audit was created.
- By 1998, with the availability of funds for the *Special Diabetes Program for Indians*, alterations in the diabetes audit led to the creation of a diabetes patient care summary in RPMS.
- In January 2000, staff and providers from various IHS, tribal, and urban Indian health programs met in Phoenix, Arizona, to collect information on how data was being produced and used at local sites.
- During 2000 and 2001, the information collected at the January 2000 meeting was disseminated for the benefit of all people working in the field.

The applications that developed from these achievements are now known as the Diabetes Management System. The Diabetes Management System is the result of grass roots ideas that produced programs and applications based on local needs. These ideas, programs, and applications have been shared through a loose network of shareware users. Now we move into the year 2002 and beyond, we are trying to build a more formal structure to this process so the benefits of these applications will continue to be available.

Using the complex clinical data from RPMS to measure diabetes care has required us to develop new skills in data management and analysis. The following three questions, and our answers to them, illustrate some of the new skills that are required of us as we move toward the use of computerized data for program measurement and patient management.

Question #1: Why is the logic used in the diabetes audit different from the diabetes supplement?

People who read the documentation for the diabetes audit and the diabetes supplement will notice differences. These differences reflect the different purposes of the two applications. The diabetes audit describes the care given to a *population* of patients. It asks, for example, what is the rate of eye exams or the rate of A1c in our community or clinic? The diabetes supplement, on the other hand, describes the care given to an *individual* patient.

Diabetes audit

In 1998, the IHS and the Inter-Tribal Council of Arizona conducted a study to compare the electronic and manual diabetes audits as data sources for calculating diabetes-related performance measures. We asked if the electronic data accurately reflected the same data that was in a patient's medical record. To answer this question, we created an audit report from RPMS data (i.e., electronic data) and another audit from manually reviewed medical charts. We compared the two audit methods by examining the rates for each diabetes performance measure, such as blood sugar control, eye exams, and diet instruction. We found that RPMS was good at capturing data on some diabetes performance measures, such as blood glucose control, blood pressure control, and flu immunization. On the other hand, we found that it was quite poor at capturing accurate data on other performance measures, such as ACE inhibitor use, eye exams, and diet instruction. In response to these findings, the IHS rewrote the definitions for the next version of the electronic diabetes audit. After the 1999 diabetes audit, we conducted the study again. This time, we created an EpiInfo file for both RPMS and the medical charts so that we could compare the two in a more robust fashion. Using this new methodology and with the rewritten definitions, we found that RPMS and the medical charts had an observed agreement of 91%.

Diabetes supplement

The diabetes supplement is a one-page health summary that focuses on select diabetes care items. It is used to help prompt services when a patient visits a clinic. Many IHS Areas, particularly the Alaska Area, have used this information to organize their visit planning processes. Figure 1 displays a portion of the patient care supplement. The summary quickly provides information on eye, foot, and dental exams.

```
In past 12 months:
Diabetic Eye Exam:    Maybe    Oct 24, 2001   (Visit to
Ophthalmologist/Optometrist)
Diabetic Foot Exam:     Yes     Mar 07, 2002   (Diabetic
Foot Exam, Complete)
Dental Exam:            No
```

Figure 1. Portion of a patient care supplement that displays information on foot, eye, and dental exams

To reflect the outcomes for a group audit, we found it worked best to include any type of visit to an eye professional as evidence of an annual diabetes eye exam. This was true because a visit to an eye professional usually included an adequate examination of the retina. Audits using these criteria replicated manual chart audit results very closely. However, for an individual patient, it was very important to know exactly whether or not an adequate eye examination had occurred. Therefore, we had to qualify the criteria to state whether a complete eye exam had occurred (i.e., "Yes") or only whether we knew if a patient had seen an eye professional (i.e., "Maybe"). This type of minor, yet important, difference is repeated in several places throughout the audit and supplement.

Lessons learned

We learned several lessons from the diabetes audits and supplements. First, the level of specificity required to reflect care for an individual patient is different from that required to determine care for a group of patients. Second, we still need to develop better methods for displaying data, and we need to determine which of the measures are important for us to display.

Question #2: Did we really show an improvement in diabetes care, or did we only change the definitions?

Because the definitions used to create the computer applications have such a strong effect on the results, some people might ask if improvements in diabetes care reflect real improvements or merely manipulations of data definitions. I will discuss analyses of our Provider Profile process that address this question.

Since 1999, the Phoenix Indian Medical Center (PIMC) has provided provider-specific feedback to clinicians on the IHS Diabetes Standards of Care within our diabetes clinics. Provider feedback is used because informed providers can improve health care quality and because it is an integral part of job performance and satisfaction.

We selected patients who are listed in the PIMC diabetes registry and had at least four provider encounters in one year. We found that using four provider encounters decreased the probability of counting a patient in more than one provider's patient panel. While performance measures increased with the number of visits in a year, performance leveled out after two or three visits. Thus, we created fairly stable patient-provider panels for comparison.

Tobacco use is a documentation issue that requires the use of a specific health factor. Health factor documentation is something that a provider must learn to do and requires an active process. During our first examination in the fall of 1999 and spring of 2000, we found that very few providers documented tobacco use. We began to give providers feedback and instructions on how to use health factors. By late 2000, following the health factor training, we found that providers began documenting tobacco use for the patients that they saw. We measured tobacco use documentation every six months and found that documentation has continued to increase. The most recent data from July 2002 shows that documentation levels have increased to such an extent that, within confidence intervals of our sampling method, several providers have reached the idealized goals for documentation as defined by the Diabetes Quality Improvement Project.

Lessons learned

The lessons from this process are that using and providing data feedback is a quality improvement process in and of itself. You do not need to wait for your data to be perfect before you start measuring outcomes, providing feedback, and taking action.

Question #3: Why do I still have data problems even after a couple of years of dedicated data quality improvement work?

After working for several years and seeing the improvements in the documentation of tobacco use, we thought that we had achieved high data quality. We were shocked, then, when we found a high error rate when trying to identify people who needed an eye exam. The following story demonstrates what happened and what we learned from it.

One of our clinic sites was equipped with an teleophthalmology image station, which was used to obtain retinal images and transmit the images over the internet to an optometrist who could read and grade the images. As we improved our eye exam rate using the teleophthalmology technology, we decided to target people from our diabetes registry who had not received retinal eye exams. When we contacted these people, they responded angrily, saying, "I do not have diabetes, so why do you say that I need a retinal exam?" We were very surprised to learn that these people on our registry did not have diabetes. We had worked hard to clean up our diabetes registry and make is as accurate as possible. So, we decided to examine the sensitivity, specificity, and predictive value of our diabetes registry and clean up any incorrect data as necessary.

Our previous studies indicated that our diabetes registries were 93% sensitive and 99.3% specific with a positive predictive value of 95%. In other words, 95% of the people in our registry really did have diabetes. We felt that was a very good positive predictive value, especially when we knew that our registry was relatively large with many people being added and removed from the registry at any given time. However, even though our diabetes registry was greater than 95% accurate, the data were still not perfect. For example, if we examined a group of 1,000 people in a registry with 95% accuracy, 950 of those people would have diabetes and 50 of these people would not have diabetes. If everybody in your registry has *not* had a retinal exam and you send 1,000 letters to them asking them to visit the clinic, 5% or 50 of the letters will go to people who do not have diabetes (i.e., equal to the 5% false positive rate). This also means that your mailing will have had a 5% error rate. On the other hand, if everybody in your registry *with diabetes* has had a retinal exam, then you will only mail out 50 letters and those 50 letters will go to the 50

people who do not have diabetes because they are the only ones who have not received a retinal exam. While you are sending out fewer letters, your mailing now has a 100% error rate. As the new technology helped us improve our eye exam rate, we experienced this exact finding.

When we started, approximately 50% of the people in our registry had received a retinal exam, and our mailing had an 8% error rate. As we continued to improve our screening rates, our mailing error rate tripled from 8 to 24%.

Lessons learned
Even very, very good data will have errors. You should be ready to communicate this to patients and staff and be prepared to explain that data quality improvement is a continuous process. Communication can help people understand this and maintain the confidence in using such complex data systems.

What does the future hold for improving data quality?
In addition to trial and error and learning, there are things we can do to help our data systems work more effectively and efficiently. First, we can help foster collaboration among providers, site managers, data entry staff, and clinic coordinators to improve data quality. No single person or department alone can do it. Second, we can encourage "official" training for the Diabetes Management System. There are many features and tricks that can be picked up with proper training. Third, we can encourage networking with other users and learning from one another through conferences and e-mail.

What does the future hold for improving data use?
Over the next two to three years, we will see many improvements to our Diabetes Management System that will encourage wider use. These improvements will include an increased growth in the availability of training and a general improvement in data quality through applications like PCC+. I believe we will see more and more direct data entry through keyboard and screen entry applications. I believe we will see more hybrid auditing where we use both electronic and manual charts reviews to complement each other while at the same time improving work efficiency. We will network more effectively through web boards, e-mail list-serves, and chat rooms, where people can share their ideas quickly and efficiently. We will also have a graphic user interface (GUI) for RPMS. Finally, we will develop innovative interfaces between applications, such as interfaces between handheld computers (e.g., Palm Pilots) and RPMS.

The Diabetes Management System has grown because of the sharing of ideas through an ongoing grass roots effort to improve care for the people in our communities who are affected by diabetes. This innovation will continue to result in an increase in data quality and data use.

Plenary Session

Emerging Technologies and New Challenges for Patient Care and Population Based Reporting

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Indian Health Service

Purpose

To describe the various information systems that are currently available to the Indian Health Service (IHS), tribal, and urban Indian health programs, and discuss the long-range plans for these systems.

Are emerging technologies a solution?

Emerging technologies are not a solution for improving health care. Rather, emerging technologies can *help* us improve care, but they are not the only way to reach that goal. The IHS Information Technology Support Center has historically said that your work and lives will be better if we produce new software for your use. The reality is really not so simple. Your work and lives will be better if we produce new software and information technology tools in conjunction with end users. These tools will then be integrated into clinical processes via appropriate business process re-engineering.

Social capital, public health, and diabetes

Social capital can be defined as a collection of the associations, relationships, and bonds that foster trust and group strength in communities. Strong social capital can help communities in various areas—the economy and health of a community are two examples—because social capital facilitates access to information and resources from a large number of individuals and communities. Social capital can help expand the datasets that are available for collection and evaluation. From a public health perspective, the social capital model is dependent upon our ability to *identify* the data elements that are needed. Then, we can evaluate these elements and determine their effect on health care. Identification of the data elements and requirements is a major driver for emerging technologies, such as telemedicine, handhelds, internet access, and Joslin Retinal Screenings.

Telemedicine

Many sites are already using telemedicine. This has helped resolve many of the issues related to treating patients in remote areas. Because of the rural nature of most of the communities served by the IHS, telemedicine has the ability to have a tremendous and ongoing effect on the health status of people in those communities. Furthermore, with telemedicine, a site does not need to invest thousands of dollars in medical and diagnostic equipment. For example, if a provider at a tribal clinic sees a person who has a dermatology lesion, the provider can take a photograph of the lesion with a digital camera and e-mail the photograph to specialists for consultation and review.

Handhelds

Many IHS providers currently use handhelds. Our research shows that there is endemic use of handhelds if you are less than 35 years of age; age is the predictor of who is using a handheld and how effective they are. IHS data also show that providers consistently use their handhelds for pharmacy information. In the next five years, the IHS expects that providers will use handhelds to record increasing amounts of information, which could be electronically transmitted to any site. The IHS is also developing an electronic tablet, which can be used by a provider to record information on a patient. The information on the tablet could then be downloaded into the Resource and Patient Management System (RPMS).

Indian Health Performance Evaluation System (IHPES)

The IHPES (formerly known as the ORYX Initiative) is dedicated to increasing the relevance of accreditation, an important building block for supporting quality improvement efforts in accredited organizations. IHPES activities include classroom education (e.g., data quality improvement courses), data quality laptop assessments (e.g., an application that contains aggregated findings as well as improvement recommendations), a web site that includes web-based data and tools, bidirectional feed of data, and the development of early alert systems.

Future applications and technologies

What do we want from new technology? What do we need from new technology? How much will a new technology or application cost? How much will it cost to provide field support? And, in the end, will the new technology really make a difference?

New technologies must support clinical improvements across multiple preventive and clinical domains. They must also be adaptive as science changes, acceptable to providers (i.e., not just physicians, but also family members), and aligned with facility and tribal goals. New technologies should also be able to enhance the data that we collect, thereby improving our ability to measure co-morbidity, medication adherence, continuity of care, individual outcome measures, population health outcome measures, and public health measures.

The IHS plans to develop a population health module for RPMS. Currently, when you produce a health summary from RPMS, you obtain only individual-based health information. You are not able to obtain any community-based health information on that patient, despite the fact that your model of health care is one of community-oriented primary care. Our goal for this new technology is to enable you to have access to information on public health laws, immunization levels, and fluoridation levels for the community where your patient lives. This will help you make better decisions for your patients within the context of their communities.

Graphic User Interface (GUI)

GUIs provide full functionality, meaning that the user can view data, as well as easily add, delete, or modify information for certain clinical applications. They have many benefits, including accurate and timely data entry, timely data retrieval, and a user-friendly interface (see Figure 1). Currently, the RPMS patient chart uses a GUI, and a GUI version of the diabetes module will be available soon. The GUI provides full functionality, meaning that the user can easily modify, add, delete, or change information.

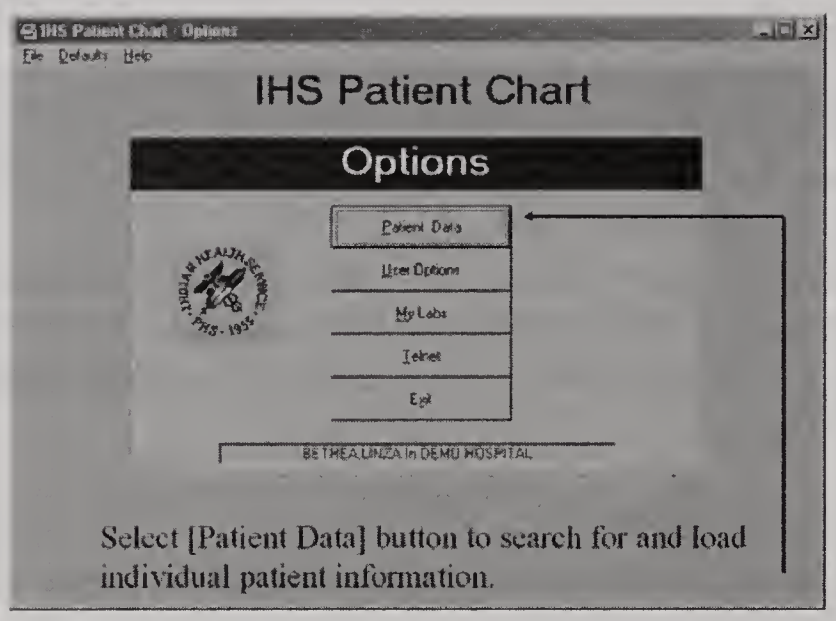

Figure 1. GUI for the IHS patient chart

The GUI also enables the user to produce custom charts and graphs (see Figure 2), which can be used to share with the patient. For example, I recently had a patient with decreasing A1c levels because she was compliant and losing weight. I produced several graphs of her A1c levels, weight, and blood pressure, and gave them to her. Although she stated that she did not understand the numbers, she thought the graphs were "awesome." She could finally *see* the difference.

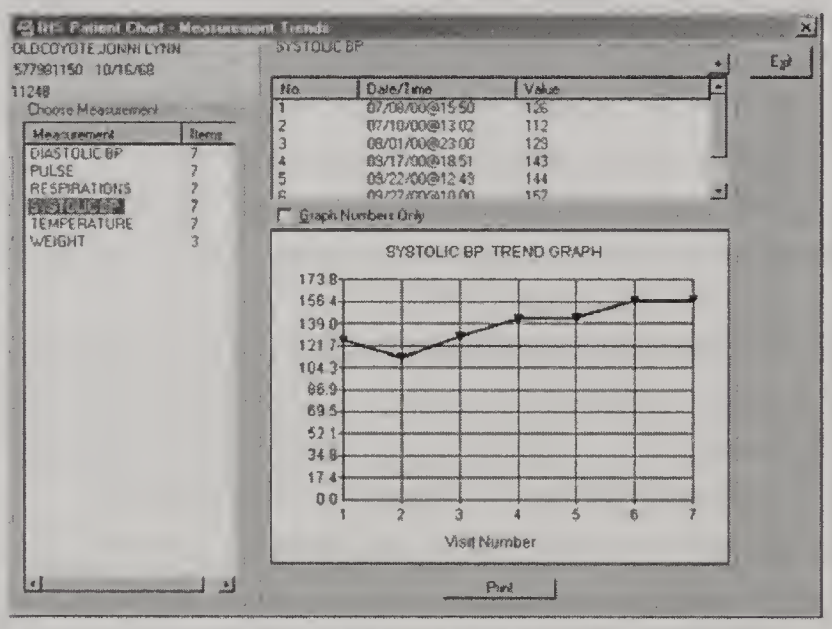
SYSTOLIC BP TREND GRAPH
Visit Number
To graph results, highlight the appropriate data. Details will be displayed in the upper box.

Figure 2. Graphs produced by the GUI in the IHS patient chart

Crossing the quality chasm

Two major recommendations for facilities are that they: 1) have computerized provider order entry (CPOE); and 2) have intensivist staffing for intensive care units (ICUs). The IHS has neither of these right now, and they are very important for improving the quality of care.

CPOE involves using a computer to place orders for medications. CPOE has been proven to save lives, save money, improve adherence to formularies, and decrease cost. It is a real time decision making tool; allows direct provider data entry; analyzes data input through clinical rules-based system edits; flags dosing errors, drug interactions, and drug allergies; assesses what to order and treat; displays relevant information; and provides advisory prompts to the provider. In response to a federal CPOE initiative, the IHS is in the process of developing CPOE and should make it available by 2004. Note that you must be running a GUI and be on PCs, not terminals, to use CPOE.

Although intensivist staffing in ICUs is expensive, data show that mortality is reduced by 40% when patients are cared for by intensivists rather than family practitioners. Because intensivist staffing may not be reasonable for many rural sites, telemedicine may be able to give those sites 24-hour coverage with an intensivist.

In addition to CPOE and intensivist staffing, several other emerging technologies should help the IHS cross the quality chasm. First, hospital bar coding is currently available at some sites and will be available in the near future to all sites. Hospital bar coding helps pharmacies decrease mistakes by checking the patients (e.g., for allergies), dose, route, time, and drug (e.g., for correct medication). Second, the IHS is working with the Joslin Diabetes Center to develop a comprehensive diabetes management system, which should be available by 2005. See Figure 3 for sample screens from the comprehensive diabetes management system.

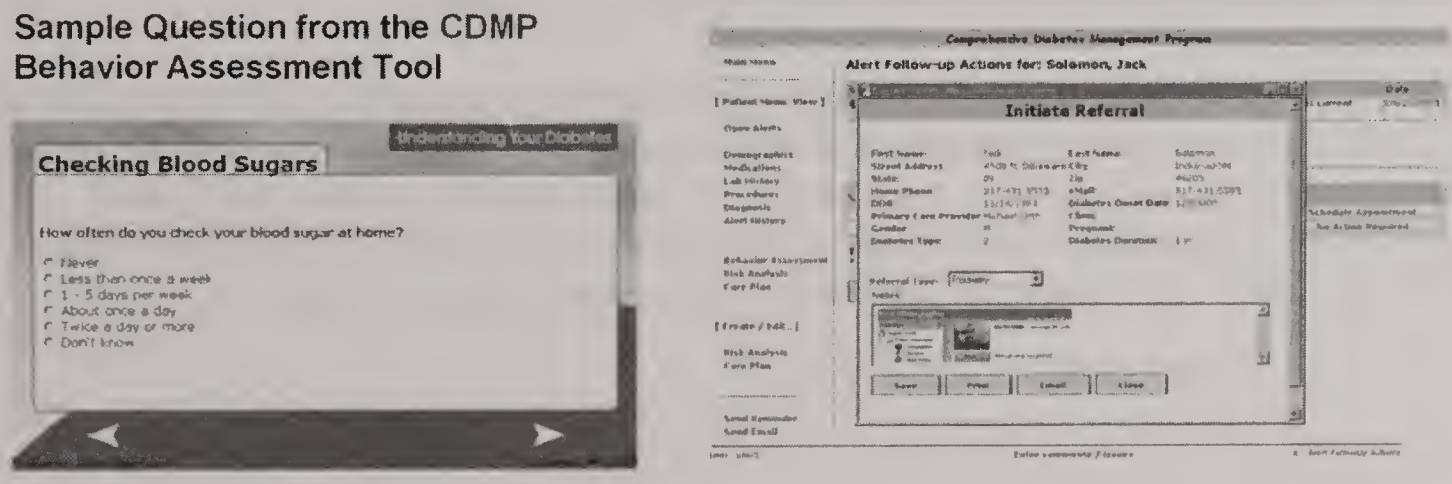
Sample Question from the CDMP
Behavior Assessment Tool
Understanding Your Diabetes
Checking Blood Sugars
How often do you check your blood sugar at home?
Never
Less than once a week
1 - 5 days per week
About once a day
Twice a day or more
Don't know
Comprehensive Diabetes Management Program
Alert Follow-up Actions for: Solomon, Jack
Initiate Referral

Figure 3. Sample screens from the Joslin Diabetes Center Comprehensive Diabetes Management System

Third, the internet can help patients obtain health information (e.g., through internet portals at health clinics). The current thinking is that IHS patients do not use the internet. The Bill and Melinda Gates Foundation has funded a grant at the University of Washington that is looking at health care access via the internet for American Indians and Alaska Natives (AI/ANs). Their data indicate that AI/ANs, no matter how isolated they are, are looking at the internet for health information. In response to this data, the IHS has placed a pilot internet kiosk in Tuba City, Arizona. Also in development are: 1) web-enabled laboratory sites where a provider can enter, view, and change laboratory data and interface with the patient record; 2) web-based diabetes tracking systems; and 3) web-based tools to track data, enter recommended monitoring, and obtain reminders. In the future, the IHS will also provide technology that will allow a patient to

upload his or her health information, like today's blood pressure, which would then be followed-up with an e-mail to the patient that tells him or her to follow some easy-to-understand instructions.

The internet has many sites where you can obtain health information. In fact, if a person types "diabetes" in a search engine, their internet search will result in over 3,000 hits. Many people do not know where to start when faced with so many hits. And, with over 65% of patients obtaining health information from the web—some from reliable sources and some not—providers and health care workers need to help their patients find useful and helpful information on the internet. Several helpful sites for providers and patients include:

- The website www.guidelines.gov enables you to view and compare guidelines for various conditions and diseases. This website is accessible from the clinical information resource page maintained by the IHS website.
- The Centers for Disease Control and Prevention (CDC) website at www.cdc.gov and the National Diabetes Education Program website at www.ndep.nih.gov both provide helpful information on diabetes.

What does the future hold?

The Centers for Medicaid and Medicare Services envisions that providers and patients will be able to monitor diabetes around the clock at home, obtain streaming real-time video from your home, simply push a button to check blood sugar or give intravenous glucose, and easily transfer information to the most appropriate personnel for any given situation.

Potential obstacles to emerging technologies include obtaining the necessary human and fiscal resources, obtaining buy-in and commitment from your providers and facilities, and developing a clear vision of where you and your site want to go. Overcoming these hurdles will prove worthwhile because the benefits of emerging technologies are numerous, including healthier communities, providing compassionate quality care, and embracing innovation.

Level I Workshops

Level I Workshop

The Basics of the Diabetes Audit

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Purpose
To describe the general history of the diabetes audit, the general methods of performing an audit, and the reports that can be generated from audit activities.

History of the Indian Health Service (IHS) Diabetes Care and Outcomes Audit
The IHS Diabetes Care and Outcomes Audit (diabetes audit) began as a series of pilot programs at the IHS National Diabetes Program Model Diabetes Program sites in the 1980s. During the early- and mid-1980s, most of the diabetes audit activities occurred at local programs. It was not until the mid-1980s when Dorothy Gohdes, along with Kelly Acton, then-Area Diabetes Consultant for the Billings Area, and Fran Stracqualursi from the Aberdeen Area, began an Area-wide diabetes audit in the Billings Area. Dr. Gohdes and her colleagues used the diabetes audit to examine the quality of care in the Billings Area both pre- and post-distribution of the IHS Diabetes Standards of Care, which had just been developed. They studied the diabetes audit results and used the data to guide improvements. For example, they implemented patient and professional education programs and improved the acquisition of laboratory data to improve the level of diabetes care. Following the implementation of these activities, they conducted another diabetes audit in 1988, which documented substantial increases in the rates of immunizations, patient education, laboratory data, and various exams. By 1990, other IHS Areas began to conduct the diabetes audit as well.

In the early 1990s, an EpiInfo program was developed that could computerize the diabetes audit. The IHS distributed the computerized diabetes audit files to the different Areas and requested that each Area send back their computerized data. Similarly, a Resource and Patient Management (RPMS) program was in development that would allow people to conduct the diabetes audit in RPMS. However, this RPMS diabetes audit program would not produce data files that were readable by EpiInfo. By 1996, a bridge was developed between RPMS and EpiInfo that would convert the diabetes audit data generated by RPMS into a file readable by EpiInfo. This bridge ensured that all the data would be in a single format, allowing the IHS to aggregate the data to obtain a national picture of diabetes care.

The diabetes audit continues to use EpiInfo to computerize the diabetes audit data. Every year, the IHS sends out a set of diabetes audit instructions that describes the process of the diabetes audit, the use of EpiInfo, the process of pulling the correct number of medical charts, information on who to include and exclude in the medical chart reviews, and a standard definition for each diabetes audit element.

The two methods of the diabetes audit

The two methods used to perform the diabetes audit are the manual chart review and the electronic diabetes audit through RPMS. The manual chart review is more labor-intensive than an electronic diabetes audit because it involves reviewing each individual medical chart and manually completing the diabetes audit form for each chart. In addition, the manual chart review requires that reviewers be familiar with the diabetes audit definitions to ensure that each Area submits uniform data. After the diabetes audit forms are manually completed, the data must be entered into EpiInfo. Once the data are in EpiInfo, you can analyze your data, produce reports, and send the reports to your Area Diabetes Consultant.

The electronic diabetes audit is not as labor-intensive as the manual diabetes audit, but it does require that you set-up system security keys and develop taxonomies. Once you complete this set-up process, you will run the diabetes audit through the Diabetes Management System (DMS) in RPMS and ultimately produce an EpiInfo file, which you will send to your Area Diabetes Consultant. The steps to complete a diabetes audit in DMS were reviewed in the "Introduction to the Diabetes Management System" workshop.

Both the manual chart review and the electronic diabetes audit have the potential to be excellent methods, but there are some drawbacks to both methods. The manual method is labor-intensive and is dependent on the conscientiousness and level of expertise of your reviewers. However, it is not dependent on an entire system of data entry into RPMS. The electronic diabetes audit is much easier once it is set-up, but it requires the expertise of someone in your facility to set it up. While I do not want to convert you to one method or the other, I would encourage you to be flexible. If you like the manual audit, why not consider the electronic method as well? By testing both methods, you will be able to see how well RPMS captures your data. If RPMS captures the data well and the two methods yield similar diabetes audit results, you may be convinced to use the electronic method exclusively. If the manual and electronic diabetes audits do not yield similar results, you may want to address the problem areas.

Size-adjustment of the audit data

Once the data are sent to the Area level, they are aggregated to form the Area diabetes report. In my current role with the IHS, I aggregate the data from all 12 IHS Areas into one national file. To ensure that each of these datasets is representative of the care at the Area and national levels, we perform a size-adjustment on the data. Using SAS and other statistical programs, Betty Skipper, a biostatistician at the University of New Mexico, performs the size-adjustments to the data. The final results are distributed to the Area Diabetes Consultants and the IHS National Diabetes Program.

Producing diabetes audit reports

You can produce three pre-programmed reports from EpiInfo: 1) the standard diabetes audit summary report; 2) a kidney preservation report; and 3) a cardiovascular disease risk factor report. The standard diabetes audit report lists the number of charts that were reviewed and provides a list of demographic information with the number and percent of people audited for each category. For example, if you are interested in the number of people at your facility who had a dental exam in the past year, the standard audit report will show you the number and percent of patients who had the exam in the preceding year. If interested, you can then contact

your Area Diabetes Consultant and find out how your facility compared with the rest of the country or with another Area.

Level I Workshop

Creating a Diabetes Registry: From Shoebox to RPMS

James Oliver, RD
Western Tribal Diabetes Project
Northwest Portland Area Indian Health Board

Purpose

To provide an overview of how to create a Resource and Patient Management System (RPMS) diabetes registry by describing reasons for using the registry, issues you should consider before deciding to use one, and instructions on how to set-up a registry.

What is an RPMS diabetes registry?

The RPMS diabetes registry is an electronic system used to track information on your patients with diabetes. The information that you can track includes the onset date, laboratory values, medications, and complications. A clinician who delivers diabetes care and education to a reservation community would want to use a diabetes registry to maintain an accurate list of people with diabetes and provide a system to easily recall these people for follow-up care. These two uses of a diabetes registry are fulfilled by both electronic registries and manual registries. However, the electronic RPMS diabetes registry can also provide clinicians with information and systems not available through a manual registry, such as access to health information including laboratory values, medications, diabetes education, and exams; access to reporting features including follow-up letters; and simplifying the Indian Health Service (IHS) Diabetes Care and Outcomes Audit (diabetes audit) process.

Key issues to consider before you start a registry

Although building a registry is easy, maintaining it can be a challenge. At minimum, the registry requires accurate documentation and timely data entry, buy-in from the entire clinic staff, and RPMS support to install patches and updates and troubleshoot RPMS. The Diabetes Data Capacity Pyramid, displayed in Figure 1, illustrates a number of other issues that you should consider, such as your data systems capacity, administrative support, on-site IT support, and access to RPMS with current packages.

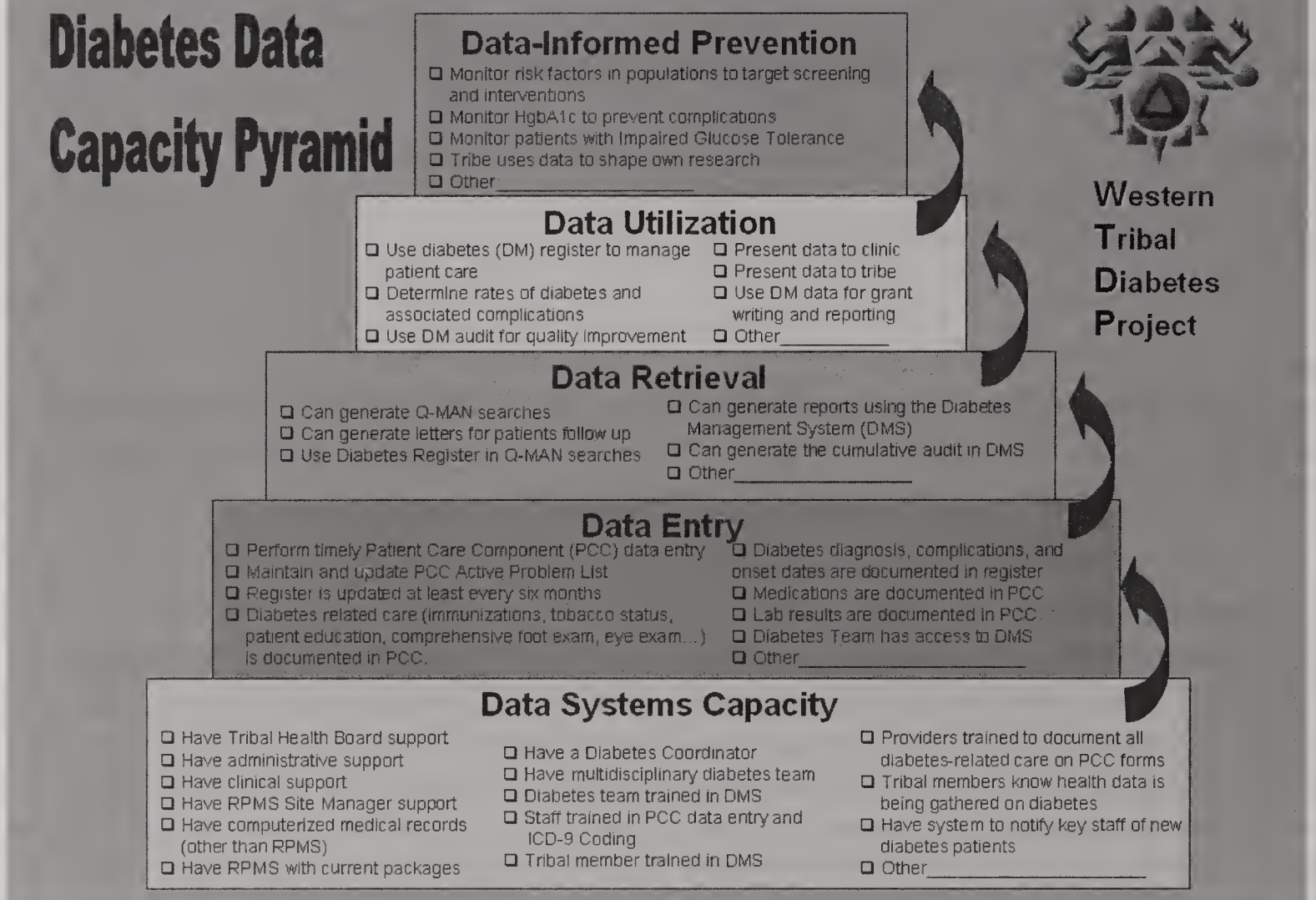
Diabetes Data Capacity Pyramid
Data-Informed Prevention
❑ Monitor risk factors in populations to target screening and interventions
❑ Monitor HgbA1c to prevent complications
❑ Monitor patients with Impaired Glucose Tolerance
❑ Tribe uses data to shape own research
❑ Other_____
Data Utilization
❑ Use diabetes (DM) register to manage patient care
❑ Determine rates of diabetes and associated complications
❑ Use DM audit for quality improvement
❑ Present data to clinic
❑ Present data to tribe
❑ Use DM data for grant writing and reporting
❑ Other_____
Data Retrieval
❑ Can generate Q-MAN searches
❑ Can generate letters for patients follow up
❑ Use Diabetes Register in Q-MAN searches
❑ Can generate reports using the Diabetes Management System (DMS)
❑ Can generate the cumulative audit in DMS
❑ Other_____
Data Entry
❑ Perform timely Patient Care Component (PCC) data entry
❑ Maintain and update PCC Active Problem List
❑ Register is updated at least every six months
❑ Diabetes related care (immunizations, tobacco status, patient education, comprehensive foot exam, eye exam...) is documented in PCC.
❑ Diabetes diagnosis, complications, and onset dates are documented in register
❑ Medications are documented in PCC
❑ Lab results are documented in PCC
❑ Diabetes Team has access to DMS
❑ Other_____
Data Systems Capacity
❑ Have Tribal Health Board support
❑ Have administrative support
❑ Have clinical support
❑ Have RPMS Site Manager support
❑ Have computerized medical records (other than RPMS)
❑ Have RPMS with current packages
❑ Have a Diabetes Coordinator
❑ Have multidisciplinary diabetes team
❑ Diabetes team trained in DMS
❑ Staff trained in PCC data entry and ICD-9 Coding
❑ Tribal member trained in DMS
❑ Providers trained to document all diabetes-related care on PCC forms
❑ Tribal members know health data is being gathered on diabetes
❑ Have system to notify key staff of new diabetes patients
❑ Other_____
Western Tribal Diabetes Project

Figure 1. Diabetes Data Capacity Pyramid

Getting started

Step One: Define the status of patients in your registry

- Active patients: Patients who receive their primary diabetes care at your clinic
  Example: Patients who have had a diabetes clinic visit in the last 12 months
- Transient patients: Patients who use your clinic, but not for diabetes care
  Example: Patients who have had non-diabetes clinic visits in the last 12 months
- Inactive patients: Patients who do not regularly use your clinic
  Example: Patients who have not had a visit in the last 12 months
- Lost to follow-up: Patients who have not used your clinic for an extended period of time
  Example: Patients who have not had a visit in the last three years
- Unreviewed: Patients whose charts have not yet been reviewed
- Deceased

Step Two: Choose the complications that you want to track

Do not choose too many complications to track. Prioritize the complications that are important to you. In the Portland Area, the following complications are commonly tracked: Proteinuria,

hypertension, hyperlipidemia, heart attack, stroke, neuropathy, end-stage kidney disease, retinopathy, and lower extremity amputation.

Step Three: Select a time frame for reviewing charts
This involves reviewing charts to find information that may be missing from your diabetes registry. Be realistic; common time frames for chart reviews are quarterly, semi-annual, and annual chart reviews. The amount of work will depend upon the completeness of your data entry.

Step Four: Create the diabetes registry in the Case Management System (CMS)
When you create the diabetes registry, the name of your registry must contain the full word "diabetes."

Step Five: Add authorized users of your diabetes registry
Even though you just created the registry, you still need to add yourself to the list of authorized users.

Step Six: Create and modify the list of complications that you decided to track
You can do this from the Registry Maintenance Menu of the Diabetes Management System (DMS). Although a partial list of complications is built into the system, you can easily add other complications into the system.

Step Seven: Create a list of active clinic users who have diabetes
This list is also known as a Q-Man search template. You will save a list of people who probably have diabetes based on ICD-9 codes, but this list will contain a certain number of people who have been miscoded and do not have diabetes.

Step Eight: Transfer the list of patients into your diabetes registry
During this step, you will electronically transfer the list from the Q-Man search to your diabetes registry. You will need to mark each record as "unreviewed."

Step Nine: Print a master list of "unreviewed" patients
You can do this from the Reports menu of DMS and review the list for obvious mistakes.

Step Ten: Review charts
Because everyone in your diabetes registry has a status of "unreviewed," you will need to review each chart to confirm the diabetes diagnosis. This is the most time-consuming step. Review the entire chart—not just the health summary or flow sheet. Figure 2 displays a sample chart review form. When reviewing the charts, look for diagnoses and onset dates in the Patient Care Component (PCC) forms (or progress notes), consultation notes, or diabetes flow sheets; look for complications before the onset of diabetes; and check the chronic medication list. Keep in mind that you may need to examine and review archived charts.

Patient Name:_____

Chart No:_____

Primary Provider:_____

DM diagnosis with onset date:

- ❑ Type 1 – onset:_____
- ❑ Type 2 – onset:_____
- ❑ IGT – onset:_____
- ❑ GDM – onset:_____

Status:

- ❑ Active
- ❑ Inactive
- ❑ Lost to follow-up
- ❑ Transient
- ❑ Non-IHS
- ❑ Deceased

Complications with onset date:

- ❑ LEA – onset:_____
- ❑ CVA – onset:_____
- ❑ ESRD – onset:_____
- ❑ Hyperlipidemia – onset:__
- ❑ Hypertension – onset:____
- ❑ MI – onset:_____
- ❑ Neuropathy – onset:_____
- ❑ Proteinuria – onset:_____
- ❑ Retinopathy – onset:_____

Other complications:

- ❑ _____ – onset:_____
- ❑ _____ – onset:_____
- ❑ _____ – onset:_____
- ❑ _____ – onset:_____

Figure 2. Sample chart review form

Step Eleven: Update the registry data
You will do this from the Patient Management screen of DMS, which is displayed in Figure 3. You can edit and update the status (e.g., change from "unreviewed" to "active"), last review (e.g., when you reviewed the chart), next review (e.g., date when you will re-review the chart), diagnosis, and onset date fields in the diabetes registry.

Step Twelve: Print an updated master list
After you complete the chart review and update the registry data, print a report that is sorted first by status and then by patient. This creates an alphabetical list of patients within each status (i.e., active, inactive, transient, etc.). This will help you prioritize patients.

Step Thirteen: Set up the diabetes audit taxonomies
You must set up taxonomies so that DMS knows what to look for when you run the diabetes audit.

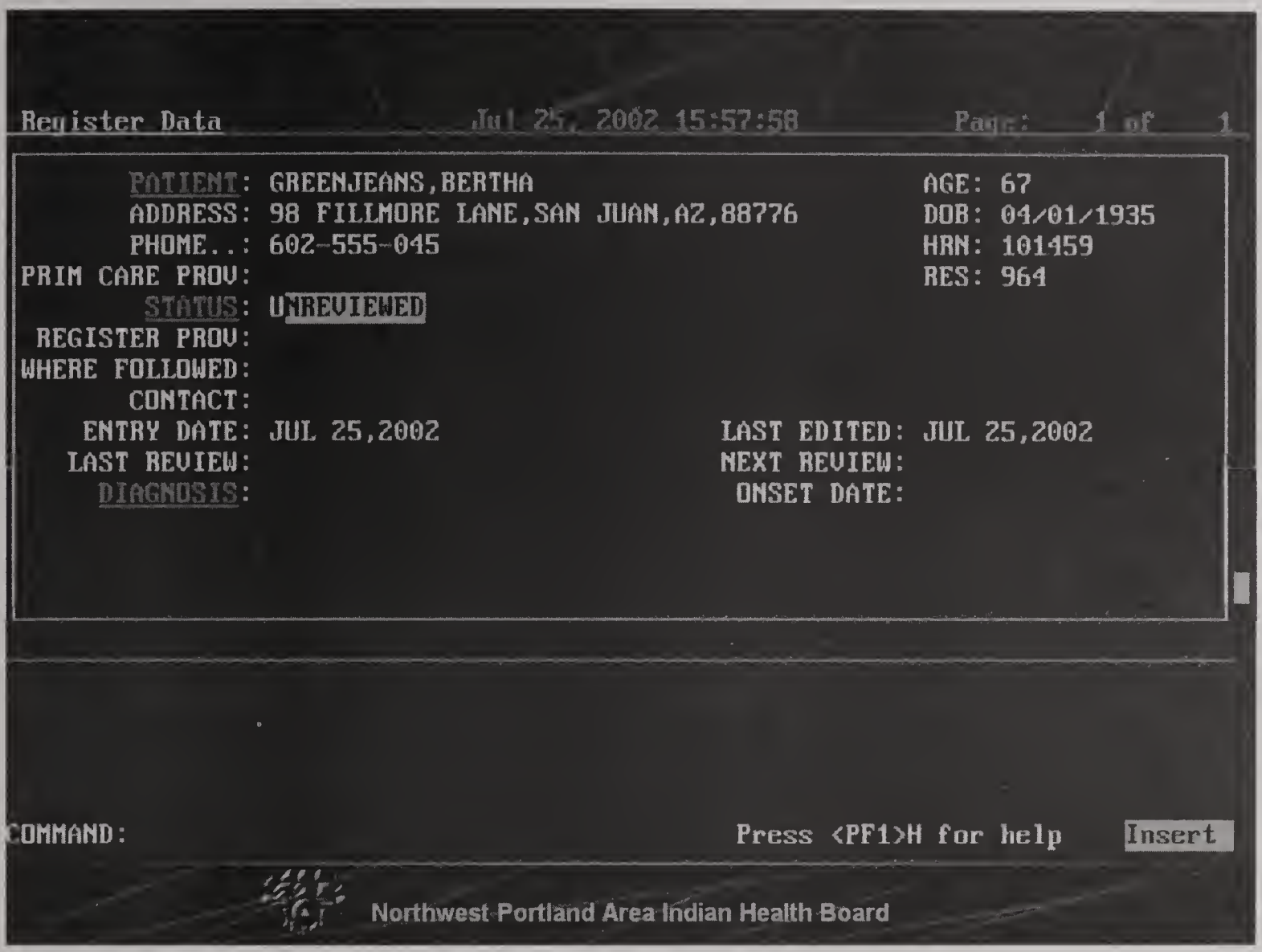
Register Data Jul 25, 2002 15:57:58 Page: 1 of 1
PATIENT: GREENJEANS,BERTHA AGE: 67
ADDRESS: 98 FILLMORE LANE,SAN JUAN,AZ,88776 DOB: 04/01/1935
PHONE..: 602-555-045 HRN: 101459
PRIM CARE PROV: RES: 964
STATUS: UNREVIEWED
REGISTER PROV:
WHERE FOLLOWED:
CONTACT:
ENTRY DATE: JUL 25,2002 LAST EDITED: JUL 25,2002
LAST REVIEW: NEXT REVIEW:
DIAGNOSIS: ONSET DATE:
COMMAND: Press <PF1>H for help Insert
Northwest Portland Area Indian Health Board

Figure 3. Patient Management Screen in DMS

Maintaining your diabetes registry

The result of creating a diabetes registry, reviewing the medical charts, and updating your registry is a list of people at your clinic who have diabetes. The list of patients in your diabetes registry is much more accurate than what you would obtain from a Q-Man search, for example. However, maintaining the diabetes registry can be a challenge. Strategies for maintaining your registry include:

- Stay on top of data entry.
- Periodically review your master list for obvious mistakes (repeat step nine).
- Update statuses often (e.g., an "inactive" patient may become "active").
- Stay on top of chart reviews.
- Use mailman bulletins within DMS to automatically send an e-mail to you when somebody at your clinic is diagnosed with diabetes.
- Route PCC copies and charts to Diabetes Coordinators for monitoring of care.
- Periodically run a Q-Man search for patients diagnosed with diabetes who are not in your diabetes registry and review those charts. (Do *not* electronically transfer the results of

your Q-Man search into your diabetes registry because you want the registry to contain only the patients whom you confirmed have been diagnosed with diabetes.)

Level I Workshop

Diabetes Audit for Non-Indian Health Service Facilities

Janice White, MPH
Indian Health Service Nashville Area
United South and Eastern Tribes Epidemiology Program

Purpose
To describe methods to obtain data from Contract Health Service (CHS) providers.

Why do we collect diabetes data?
We collect diabetes data for many reasons:

- Case management: What kind of conditions do your patients have? What kind of treatments are they receiving? Are we doing any good with our interventions?
- Epidemiologic purposes
- Program planning, management, and evaluation
- Grant and funding opportunities: How can we obtain more money for our programs to affect the care and lives of individuals?

The Nashville Diabetes Surveillance and Audit Project
In 1997, with the inception of the *Special Diabetes Program for Indians*, Congress directed the Indian Health Service (IHS) to conduct surveillance on five data elements: prevalence, obesity, amputations, end-stage kidney disease, and retinopathy. When we began collecting data on these required elements, some sites and IHS Areas reported that they could not collect the data because the data were not in their systems. In response, the IHS National Diabetes Program instructed those sites to complete the IHS Diabetes Care and Outcomes Audit (diabetes audit) in lieu of conducting surveillance on the five data elements. The Nashville Area, however, did not give our sites a choice. Our tribal health directors and tribal leaders mandated the tribes to do both the audit *and* surveillance. As a result, the Nashville Area established the Nashville Diabetes Surveillance and Audit Project for which every tribe in the Nashville Area conducts surveillance on diabetes prevalence, obesity rates for adults and children, gestational diabetes incidence and crossover, and impaired glucose tolerance incidence and crossover.

At the end of the first year of the project, we had accomplished several goals. First, we developed definitions for each of the five surveillance elements. Second, we held diabetes management registry trainings at every site and helped each site develop their diabetes registries. Third, we conducted chart reviews to confirm the diabetes diagnoses of patients in the diabetes registries. However, during these chart reviews, we found a lot of people who were miscoded as having diabetes. Although we were able to clean up the registries and remove all miscoded

patients, we found that we were missing a lot of data on diabetes complications, such as laboratory values, immunizations, and procedures.

Where were the missing data hiding?

We found that the missing data were hiding in several places. First, some of the data were in the medical charts and simply had not been entered into the Resource and Patient Management System (RPMS). Second, some individuals were visiting private providers, dialysis centers, or hospitals, and we were not receiving patient data from these locations. Third, we found that CHS physicians were not sending data back to our sites. If the CHS providers were sending information back to our clinics, they usually sent a note that went directly into the medical chart, but was not entered into RPMS.

To address the problem of the missing data, we started a pilot project called the Nashville Area Pilot Data Sharing Project: Building Diabetes Care Partnerships between Tribes and CHS Providers. Through this project, we informed our CHS-only tribes that they should participate in the case management of their diabetes patients. To do this, we found that several steps are involved in forming an effective partnership between tribes and CHS providers.

First, we asked each tribe to *take an inventory of their diabetes services*. We made a complete list of all the services that they provided and asked them to briefly describe each service.

Second, we asked each tribe to *establish and manage a diabetes registry*. At the same time, we asked each tribe to develop a plan to manage their data with the CHS primary care providers. To develop this plan, we asked tribes to consider the following questions:

- Are you going to use a flow chart or questionnaire to capture the data from the physicians?
- How is data privacy going to be maintained as you collect the information?
- How will data be transferred between the tribe and CHS providers (e.g., will tribal staff drive to the CHS provider's clinic, or will the tribe set up regular meetings to share information?
- How will releases of information be handled?
- What information or cumulative reports will you share with the providers and how often?

Third, each tribe needed to *enlist community support*. The first part of this is to gain visibility in the community. The tribes did this by networking with other health care organizations, attending neighboring community health fairs and screenings, and meeting the local hospital discharge planner. The second part of enlisting community support is to gain credibility in diabetes care by assisting CHS providers with links to the IHS and other American Indian and Alaska Native (AI/AN) care services, assisting CHS providers with a referral system back to the tribal health department, and marketing tribal health services (e.g., dietitians, community health representatives, health educators, and behavioral health counselors) to CHS providers.

Finally, each tribe worked with CHS providers to *establish and maintain relationships*. To do this, each tribe started by prioritizing the list of CHS providers who would be contacted and in what sequence. When the tribe contacted the CHS providers, the tribe cultivated its relationship with the CHS providers by explaining the tribe's interest in collaboration and by providing the IHS Diabetes Standards of Care. The key strategies that emerged were to avoid scaring the CHS providers or giving them a feeling that the tribe was watching them, and to provide them with information on why the tribe needed the data and that the process was collaborative. For each CHS provider's office, the tribe identified its primary contact so that it could obtain the data and information that it needed. The tribe also signed a partnership agreement with each CHS provider to ensure that they were committed to helping us. Each tribe then developed plans to share data, provide regular feedback, and make referrals to and from the tribal clinic. Finally, each tribe promised to run the diabetes audit six months after the beginning of each partnership to determine if the tribe was obtaining better diabetes information and if the partnership was working to effectively manage the patients.

For tribes who were not able to form partnerships with their CHS providers, we provided them with other options for collecting missing data:

- Diabetes patient management cards: Each patient receives a card that includes key pieces of information in which we are interested, such as items from the diabetes audit. The patients can carry the cards with them and check off each item as they receive the service and list the date of the service.
- Specialized flow sheets: These flow sheets remind tribal clinic staff to ask patients if they have received key services since their last visit.
- Office questionnaires.
- Annual patient surveys.
- CHS office visits for chart review.
- Follow-up phone calls to providers.
- Reporting obligations to primary care provider.
- Withhold payment: Although this works for some tribes, it may not work for other tribes or may not be a good method for relationship building.
- State immunization registries.
- Vital statistics monthly or quarterly reports on deaths.
- Database linkages: These may not be realistic at tribal level, but you can contact your Area Epidemiology Center for assistance.

Level I Workshop

Introduction to the Diabetes Management System

Bill Mason
Cimarron Medical Informatics, LLC

Purpose

To introduce the Diabetes Management System (DMS) to people who do not currently use the system or who are new users of the system, describe each element of the system, and demonstrate most of the elements of the system.

Key elements of DMS

The key elements for DMS include: 1) the establishment and maintenance of a diabetes registry; 2) the monitoring of select patient attributes or characteristics; and 3) the production of a reminder document to assist providers with visit planning, which includes information on a patient's problems, recent measurements, and current needs.

Decision #1: How do you want to maintain your diabetes registry?

A diabetes registry is a list of your active diabetes patients. When developing a registry, you should consider two major things: 1) should you limit your registry to only type 1 and type 2 diabetes patients, or 2) should you include patients with gestational diabetes and impaired glucose tolerance in the same registry? Each clinic maintains their diabetes registry using one of these two major methods, and DMS is capable of handling either method. I recommend that you develop three separate registries: One registry for type 1 and 2 diabetes patients, one registry for patients with gestational diabetes, and one registry for patients with impaired glucose tolerance (i.e., prediabetes). I also recommend that you develop separate diabetes registries for high-risk groups, such as children with diabetic parents.

Decision #2: How many diabetes registries do you want in your service area?

If you are in a service area with multiple facilities, you will need to decide how many diabetes registries you would like to develop. The first option is to develop and maintain a single registry that is shared by all facilities. You should select this option if all of your facilities run off of the same computer network. The second option is to develop and maintain individual registries for each individual facility. At many places, each facility has a separate computer network. It then becomes a toss up if you decide to develop one common registry or individual registries.

What do you need to run DMS?

To run DMS, you must have the Resource and Patient Management System (RPMS) menu options and security keys for the Q-Man, Reports, and Case Management System functions. One of the most important elements of using DMS is a seamless relationship between the provider who records the data and the data entry worker who enters the data into DMS. This means that providers must record data in the appropriate places on the patient care form where data entry staff can easily and logically find the data.

Inside DMS: Patient Management System

Once you enter a chart number or patient name, DMS will pull up an "action menu," in the Patient Management System. The action menu will display data elements and action items. From here, you can view and produce a health summary, produce a list of the patient's medications, or review the patient's recent and upcoming appointments. You can use the Patient Management System to coordinate patient care with another department, produce a letter to another provider, generate a laboratory profile, or produce a flow sheet.

The health summary, which is produced by the Patient Management System, is the primary output of RPMS for improving patient care. It gives providers information on a patient's recent health history, chronic problems, and necessary preventive services. You can use the health summary to answer the following questions:

- Has a patient been screened for tobacco use?
- Is the patient using ACE inhibitors or aspirin?
- What are the results of the patient's last three blood pressure tests?
- Has the patient had an eye, foot, and dental exam in the last three months?
- Has the patient had a breast exam?
- Is the patient self-monitoring his or her blood glucose?
- Has the patient received diabetes education?
- Has the patient received a flu shot?
- Has the patient had a microalbuminuria test?

If you find the answer "no" to any of these questions, you can flag that area for follow-up. The health summary also includes the diabetes flow sheet and patient care supplement.

Inside DMS: Indian Health Service (IHS) Diabetes Care and Outcomes Audit

To run the IHS Diabetes Care and Outcomes Audit (diabetes audit), you must establish several taxonomies in DMS. For example, you will need to tell DMS which insulin medications are in use at your facility, what metformin medication is in use at your facility, and what lab tests constitute your lipid profile. Once you have established your taxonomies and are ready to run the diabetes audit, you will enter the name of your diabetes registry, choose a diabetes audit date, choose the group of people on whom you want to run the diabetes audit (e.g., individual patients, particular groups of patients, or all people in the registry), choose the patient status (e.g., active patients or inactive patients), choose the community (e.g., specific community or all communities), choose provider (e.g., specific provider or all providers), and indicate if you want a random sample and the number in that sample. DMS will also prompt you to decide what type of diabetes audit report you want to generate: 1) an individual report for each patient; 2) an EpiInfo file (the type of report that the IHS requires for the diabetes audit); 3) a cumulative report; or 4) both individual and cumulative reports.

Once the report is generated, you can examine the report for red flags, such as missing data on diabetes onset date, body mass index (BMI), and height. You can also use the report to help you prioritize your patients. For example, you might decide to prioritize all patients whose A1c level is over 8. This function can help you find those patients.

Inside DMS: Reports

The Reports function in DMS will easily and quickly generate a report for all patients within a certain parameter. Under this function, you can view a list of each of the IHS Diabetes Standards of Care and obtain a list of people who are overdue for a particular test or treatment. For example, if you want to find all of the patients who are overdue for a foot exam, DMS will prompt you to select a particular registry or all patients in the system; indicate if you want active or inactive patients; select type 1 or type 2 diabetes patients or all patients in the registry; indicate if you would like a list of the patient's upcoming appointments; select the community that you are interested in; select an individual provider or all providers; and indicate if you would like DMS to produce a letter or report. If you ask DMS to produce a letter, DMS will allow you to select a letter from your computer system. In general, these are letters that you have authored and will be used to inform patients that they are overdue for a foot exam and need to schedule a visit. From DMS, you can conduct the mail merge and print the letters.

Inside DMS: Q-Man

You can use the Q-Man function to obtain information about your diabetic population of patients. Q-Man will prompt you to select a particular registry or all patients in the system; indicate if you want active or inactive patients; and select type 1 or type 2 diabetes patients or all patients in the registry. Q-Man will then prompt you to search under certain parameters. For example, you can ask Q-Man to produce a list of the last A1c levels for each patient in your registry. You can also ask Q-Man to provide you with a list of patients who have *ever* had an A1c level over 8.2. More specifically, you can ask Q-Man to find all patients whose *last* A1c level was over 8.2. If you plan to prioritize these patients, Q-Man can provide you with the phone number and mailing address for these patients so that your clinic can contact them.

One of the most important Q-Man retrievals that every clinic should run is a search for potentially undiagnosed diabetic patients. These patients have not been diagnosed with diabetes, but they have had high glucose readings. You can ask Q-Man to find all people who have had a glucose reading of 150 or 180, for example. You can also ask Q-Man to find people who have had several high glucose readings. Nearly every time that a clinic runs this report, Q-Man finds people. These people should be a priority for every clinic.

Level I Workshop

Introduction to Q-Man and Other Tools

Bill Mason
Cimarron Medical Informatics, LLC

Purpose

To teach participants how to get information out of the Diabetes Management System (DMS) and review three types of data retrieval reports: follow-up reports, Q-Man ad hoc searches, and body-mass index (BMI) reports.

DMS manuals and resources on the web

You can access manuals and resources on DMS, including Q-Man, at the Indian Health Service (IHS) website at www.ihs.gov/Cio/RPMS/appsactiondoc.cfm. The DMS User Manual describes DMS, provides information on its appropriate use, and serves as an instructional guide for working in DMS.

Three simple DMS retrievals

You can perform several simple, basic retrievals from DMS. The first retrieval is called a Case Summary, which is a one-page brief synopsis of the information that is in your diabetes registry. You can produce a Case Summary for either a single individual or for every person in your registry. The Case Summary will provide you with brief demographic information, such as their registry status, diagnosis, and complications.

The second retrieval you can produce is a Master List of Patients. You can produce this list based on patient status (e.g., active, inactive, transient, deceased, lost to follow-up, or unreviewed), case management staff, age, community, etc.

A third type of retrieval is to produce a simple list of patients by a specific search parameter, such as type of diabetes, complications, case manager, age, sex, or community, or patient's next review date. If, for example, you chose to produce a list by next review date, you could produce a tickler file that provides you with a list of patients who are scheduled for a complete review during the coming month.

Follow-up Reports

The Follow-up Reports feature allows you to produce a list of patients who are overdue for a particular IHS Diabetes Standard of Care. These reports are the simplest to produce and, for follow-up purposes, they are the most helpful and beneficial. When you are at the DMS main menu, first select the "Reports" option and then the "Follow-up Needed Reports" option. DMS will then display all of the IHS Diabetes Standards of Care. You can select as many IHS Diabetes Standards of Care to be included in the report as you wish. Once you select the IHS Diabetes Standard of Care in which you are interested, DMS will ask you to answer a series of questions, such as:

- Do you want to search the entire registry or search by a specific parameter?
- What kind of patient status do you want to include (e.g., active, inactive, etc.)?
- What type of diagnoses do you want to include (e.g., type 1 diabetes, type 2 diabetes, etc.)?
- Do you want to view the patients' upcoming appointments? (n.b., This information can help you coordinate care and do visit planning for an upcoming appointment.)
- Do you want the report to be arranged by community or provider?
- Which community or communities do you want to include?

DMS will then ask if you would prefer to generate a follow-up report or a letter for each person. If you select follow-up report, a list of patients will be generated. For example, if you are interested in eye exams, the follow-up report will include all patients who are either overdue for their eye exam or who are due in the coming month. Patients who have had their eye exam in the past year will not be in the follow-up report. The follow-up report will be organized by community of residence and then alphabetized by patient last name. The report will also include the date of the last eye exam or an indication that the patient has had an eye exam.

If you select recall letter, DMS will produce a letter to all of the patients who fit under your specified parameters. This is a letter that you have created for each of your high priority monitoring items, such as laboratory information, eye exams, foot exams, immunizations, and education topics. For eye exams, you can produce a letter that reads, "Our records indicate that you are overdue for your eye exam. Please contact us at the clinic and schedule a visit to receive this service or help us update our records." DMS will produce this letter for all of the patients who are overdue for their eye exam or who are due in the coming month.

Q-Man Reports

The most powerful part of DMS is the ability to do Q-Man retrievals using your diabetes registry as the subject of Q-Man query. Any clinical element available in the PCC is available through these queries. A query in Q-Man consists of four elements:

- The *subject* of your search. For diabetes, you are interested in only three types of subjects: 1) patients (either living or all patients); 2) visits (not used frequently); or 3) patients in your registry.
- One or more *attributes* associated with your subject. An attribute is a simple demographic or clinical characteristic of the patient, such as age, sex, weight, education topic, laboratory result, etc.
- A *condition* associated with the attributes. If your attribute is quantifiable, you will select a condition, such as greater than, less than, date range, facility, etc.
- *Values* associated with the attributes and condition. For example, if systolic blood pressure is your attribute and "greater than" is your condition, then you would enter a number, such as "200," as your value.

Through a dialogue mode, Q-Man will interactively ask you questions about each element.

Attributes
Virtually every piece of information that is available through PCC is also available to you as an attribute through Q-Man. The types of attributes that you will choose from are demographic, clinical (i.e., all the clinical data stored in PCC but not in your registry), and display attributes. You will use demographic and clinical attributes to search under. While you will not use display attributes for search purposes, you can ask Q-Man to include the display attributes on the resulting Q-Man report. The following is a list of the most widely used attributes:

Demographic Attributes	Clinical Attributes	Display Attributes
Age	Measurements	Mailing Address
Sex	Immunizations	Mother's Name[2]
Tribe[1]	Skin Tests	Secondary Chart Numbers
Community of Residence	Lab Tests	Home Phone Number
Classification[1]	Exams	Office Phone Number
Service Unit of Residence	Visits	Birth Certificate Number
Blood Quantum	Diagnosis	Death Certificate Number
Date of Death	Purpose of Visit	Social Security Number
Death Age	Operation or Procedure	Tribal Enrollment Number
Cause of Death	Problems	
Eligibility	Medications	
Third Party Enrollment	Patient Education	
	Treatments	
	Health Factors	
	Dental Procedure	

[1] The classification attribute allows you to distinguish American Indians and Alaska Natives (AI/ANs) versus non-AI/ANs. Do not try to make this distinction using the tribe attribute because you will be required to enter a list of all the tribes.
[2] The mother's name attribute is used when you are producing a report on children.

Conditions
Q-Man includes several sets of conditions. The following are examples of basic, special, and very special conditions:

Basic Conditions	Special Conditions	Very Special Conditions
Equal (is)	Greatest	All (exists)
Greater than (over)	Smallest	Null (does not exist)
Less than (under)	First n	Any
After (since)	Last n	Relative Age
Before	New	Relative Date
Between (during)	Average	
On	Sum	
	At Least n	
	At Most n	
	Span (High–Low)	
	Change (Last–First)	
	Count	

Values
The following are examples of different values that can be used in a Q-Man query:

Value	Related Attribute
1/5/88	Date
Navajo	Tribe
¼	Blood Quantum
Tucson	Community of Residence
130/88	Blood Pressure
Penicillin	Medication
4+	Urine Protein
1:10	Rubella Titer (recorded as a ratio)

Sample Q-Man queries
Figure 1 displays several simple sample Q-Man queries.

Q-Man Query Examples

Subject	Attribute	Condition	Value
patients	diagnosis	is	hypertension
women	age	over	40
Martin,Lisa	hematocrit	less than	20
patients	tribe	is	Navajo
visit	date	since	1/1/92
visit	provider	is	Mary Brown
females	pap	null	
register (DM)	HgB A1C	over	9.0

Figure 1. Sample Q-Man queries

Outputs
Several outputs are available through Q-Man. The following is a list of Q-Man outputs:

- Display (on your computer screen)
- Print
- Count
- Produce a Cohort (of people who met your criteria and make a query template to use again or do a before and after study)
- Health Summaries
- Age Distribution Report
- Mailing Labels
- Export ASCII File to PC for use by software, such as EpiInfo, Excel, or Access

Demonstration of Q-Man through simple queries
When you enter Q-Man, the first item that you will see is a warning page. Because Q-Man gives you access to all of the clinical data in the PCC, you have access to highly confidential information that must be handled with confidentiality and sensitivity. Following this warning

page is the main menu. The option that you will use most of the time is the default called "Search the PCC Database."

The following is a description of several sample Q-Man searches that were covered during the workshop:

- Creating a template of potential patients to add to your diabetes registry
- Performing a periodic Q-Man search for new patients
- Investigating individual patients
- Identifying misdiagnosed patients or miscoded diagnoses
- Identifying patients who do not have a diagnosis of diabetes, but who may have diabetes

Consult the DMS User Manual or contact Cimarron for step-by-step instructions on additional searches.

Creating a template of potential patients to add to your diabetes registry
The following sample search identifies AI/AN patients with diabetes who live within your Service Unit communities and who meet the IHS definition of an active patient (i.e., at least one visit during the preceding three years). The result of this search is a template of patients who can be added to your diabetes registry under the "Register Maintenance – Add Patients from a Template" option.

```
What is the subject of your search?  LIVING PATIENTS // <ENTER>
```
(Note: If you do not know what your choices are at a particular prompt, enter two questions marks (??), and Q-Man will provide you with a list of your choices.)

```
Attribute of LIVING PATIENTS: DX

Enter DX: SURVEILLANCE DIABETES          DM SURV - USED BY HLTH SUMM
```
(Note: Be sure to create your diagnosis taxonomies.)

```
Members of SURVEILLANCE DIABETES Taxonomy =>  250.00 - 250.93

Enter ANOTHER DX:  <ENTER>

Want to save this DX group for future use? No// <ENTER>  (No)

SUBQUERY: Analysis of multiple DIAGNOSES

First condition of "DIAGNOSIS":  <ENTER>
```
(Note: By hitting "Enter," DMS will choose people who have had a diagnosis of diabetes at any point in time. However, I recommend adding a time frame for people who have had a diagnosis in the last three years.)

```
Attribute of LIVING PATIENTS: COMMUNITY
```
(Note: Be sure to create your community taxonomies.)

```
Enter COMMUNITY: SELLS              PIMA     ARIZONA     067     0410067
Enter ANOTHER COMMUNITY: SAN XAVIER          PIMA     ARIZONA     065
041006
Enter ANOTHER COMMUNITY: SANTA ROSA
     1   SANTA ROSA          PIMA     ARIZONA     034     0410034
Enter ANOTHER COMMUNITY: <ENTER>
```
(Note: Enter all of the communities that are included within your Service Unit. This attribute allows you to screen out patients who do not live within your cachement area but who have on one or more occasion used your facility for health care. The list of communities selected will be displayed with an option to save this group for future use.)

```
Attribute of LIVING PATIENTS: CLASSIFICATION/BENEFICIARY

Enter CLASSIFICATION: 01    INDIAN/ALASKA NATIVE        01
Enter ANOTHER CLASSIFICATION:

The following have been selected =>  INDIAN/ALASKA NATIVE

Attribute of LIVING PATIENTS: VISIT

SUBQUERY: Analysis of multiple VISITS

First condition of "VISIT": DURING THE PERIOD
```
(Note: Enter the beginning and ending dates of the three year period during which you wish to identify active patients.)

Exact starting date: **3/31/99** (MAR 31, 1999)

Exact ending date: **3/31/02** (MAR 31, 2002)

Next condition of "VISIT": **<ENTER>**

ATTRIBUTE: **<ENTER>**

Select Q-MAN OUTPUT OPTION **4 STORE results of a search in a FM search template**

Enter the name of the SEARCH TEMPLATE: **XYZ DIABETIC PTS**
(Note: XYZ should be your initials.)

Are you adding 'XYZ DIABETIC PTS' as a new SORT TEMPLATE? No//**<ENTER>** Y (Yes)

DESCRIPTION:
  No existing text
  Edit? NO// **<ENTER>**

Want to run this task in background? No// **<ENTER>** (No)

Performing a periodic Q-Man search for new patients

Sometimes health care providers inadvertently falter in notifying the Diabetes Coordinator when new cases of diabetes are diagnosed. It is therefore prudent to periodically perform the following Q-Man search to identify newly diagnosed cases. You should store the results of your search as a Q-Man template and then, in the Case Management System option for Adding Patients, transfer the patients from your template to your diabetes registry. Duplication will *not* occur if a patient to be transferred is already in the registry.

```
Subject:  Living Patients//   <ENTER>
Attribute:  DX
Enter Dx Code:  250.00-250.93  (Q-Man will display all diagnoses in the
range)
Enter Another Dx Code: <ENTER>
Do you wish to save this group of diagnosis codes?  NO  (Or YES if you wish)
First Condition:  First 1
Next Condition:  Since
Enter Exact Date:  (Enter the date that you last ran a search to identify new
cases of Diabetes)
Next Condition: <ENTER>
Next Attribute: <ENTER>

Select Q-MAN OUTPUT OPTION 4  STORE results of a search in a FM search
template

Enter the name of the SEARCH TEMPLATE: XYZ NEW DM PTS
(Note:  XYZ should be your initials.)

Are you adding 'XYZ NEW DIABETIC PTS' as a new SORT TEMPLATE? No//<ENTER> Y
(Yes)

DESCRIPTION:
  No existing text
  Edit? NO// <ENTER>

Want to run this task in background? No// <ENTER>  (No)
```

Investigating individual patients

Once patients have been added to the diabetes registry, it is often beneficial to review the medical record to determine whether they truly are diabetic, how often they have been seen, and when they had their last visit. Q-Man can be used to review an individual patient's visit record by choosing the individual patient's name as the Q-Man subject line.

```
What is the subject of your search?  LIVING PATIENTS //GREENJEANS,BARRY
```
(Note: Patient name may only be entered in the format Last Name,First Name.)

```
GREENJEANS,BARRY                    M 05-09-1963 001040010    SE 100035

Attribute of PATIENT: DX

Enter DX: ALL

First condition of "DIAGNOSIS": <ENTER>


Select Q-MAN OUTPUT OPTION 1, DISPLAY results on the screen or 2
PRINT results on paper to see the patient's visit record with the provider
narrative.
```

PATIENTS	SELLS NUMBER	ICD9 CODE	DATE OF POV	PROVIDER NARRATIVE
GREENJEANS,BARRY	100035	571.2	APR 27,2002	ALCOHOLIC CIR
GREENJEANS,BARRY	100035	250.00	APR 15,2002	DIABETES MELLITIS TYPE 2
GREENJEANS,BARRY	100035	250.00	DEC 2,1998	DM
GREENJEANS,BARRY	100035	401.9	DEC 2,1998	HTN
GREENJEANS,BARRY	100035	110.4	FEB 6,1997	INFECTED TINEA PEDIS IMPROVING
GREENJEANS,BARRY	100035	401.9	FEB 6,1997	HYPERTENSION
GREENJEANS,BARRY	100035	110.4	FEB 2,1997	TINEA PEDIS 2D INFECTED
GREENJEANS,BARRY	100035	401.9	FEB 2,1997	HYPERTENSION
GREENJEANS,BARRY	100035	924.3	FEB 2,1997	CONTUSION TO R GREAT TOE
GREENJEANS,BARRY	100035	079.9	JAN 24,1997	VIRAL SYNDROME
GREENJEANS,BARRY	100035	110.4	JAN 24,1997	TINEA PEDIS
GREENJEANS,BARRY	100035	714.0	JAN 7,1997	RA
GREENJEANS,BARRY	100035	250.00	JAN 7,1997	DM
GREENJEANS,BARRY	100035	428.0	JAN 7,1997	CHF
GREENJEANS,BARRY	100035	401.9	JAN 7,1997	HTN
GREENJEANS,BARRY	100035	V72.7	MAY 17,1996	SKIN TEST READING
GREENJEANS,BARRY	100035	V81.1	MAY 17,1996	BP CHECK
GREENJEANS,BARRY	100035	034.0	MAY 15,1996	LARYNGITIS/STREP PHARYNGITIS

Identifying misdiagnosed patients or miscoded diagnoses

This search allows you to identify patients in the population or diabetes registry who may have been misdiagnosed or miscoded with diabetes. The search is for patients who have a single diagnosis of diabetes. When you obtain the report, you will need to fix the miscoding in RPMS and you will need to fix the misdiagnoses in both the medical chart and RPMS.

What is the Subject of your search? Living Patients// **<ENTER>**
(Note: If you have already moved a template of patients into the registry, use registry as a subject and select the status of patients you wish to review.)

Attribute: **DX**

Enter Dx: **[Surveillance Diabetes**
(Note: Q-Man shows the code range and asks you to enter another Dx.)

Enter another Dx: **<ENTER>**

Do you Want to Save? NO// **<ENTER>**

First Condition of Dx: **AT MOST 1**

Next Condition of Dx: **<ENTER>**

Attribute: **<ENTER>**

Q-Man Output Options: **(Select #1 to display or #2 to print)**
(Note: This option will allow you to display or print the selected patients and to see the diagnosis narratives recorded by health care providers.)

PATIENTS (Alive)	SELLS NUMBER	ICD9 CODE	DATE OF POV	PROVIDER NARRATIVE
GRANT,KAIA	101743	250.01	DEC 29,1996	IDDM NO RETINOPATHY
FLINTSTONE,ABNER	101866	250.01	JUN 24,1999	DIABETES TYPE 1
BROWN,GLENN*	101010	250.01	APR 23,2001	DM TYPE 1
JONES,JOYCE	100276	250.00	AUG 3,1994	POSSIBLE DM
THATCHER,VERNON	100408	250.00	MAR 21,1996	**PROBABLE EARLY DIABETES MELLITU**
VON RICHTOFEN,C*	100516	250.00	NOV 8,1992	IATROGENIC DM 2D STEROIDS
FLINTSTONE,MEGAN	100557	250.00	JUN 27,1996	DIABETES MELLITUS
CARTER,VICKY*	100607	250.00	AUG 18,1994	DIABETES HOME VISIT.FOLLOW UP.P
KETCHUP,ANDY	100683	250.00	FEB 17,1994	POSSIBLE DIABETES
JACKSON,MARY	100792	250.00	APR 29,1993	**ABNORMAL DIABETES SCREEN**
WASHINGTON,LORI*	101066	250.00	OCT 11,1996	DIABETES BORDERLINE,DIET CONTRO
BROWN,JENNIFER*	101321	250.00	APR 29,1994	DIABETES TYPE II
WHEELWRIGHT,GINA	101695	250.00	JAN 30,1997	DM II
GRANT,ALBERT	101946	250.00	MAY 17,1996	**DIARRHEA PRESUMED DUE TO AMOXIC**

Identifying patients who do not have a diagnosis of diabetes, but who may have diabetes
This search is designed to identify patients who have not been diagnosed with diabetes but who may have diabetes based on two or more elevated glucose levels.

What is the Subject of your search? Living Patients// **<ENTER>**

Attribute: **DX**

Enter Dx: **250.00-250.93**
(Note: Q-Man shows the code range and asks you to enter another Dx.)

Enter another Dx: **<ENTER>**

First Condition of Dx: **NULL**

Next Condition of Dx: **<ENTER>**

Attribute: **GLUCOSE**

First Condition of Glucose: **OVER 140**
(Note: Or enter whatever threshold you might prefer.)

Next Condition of Glucose: **AT LEAST 2**
(Note: Or enter any other number you might prefer.)

Next Condition of Glucose: **<ENTER>**

Attribute: **<ENTER>**

Q-Man Output Options: **(Select #1 to display or #2 to print)**
(Note: Select Choice #1 to see the glucose values and the dates of the tests.)

Body Mass Index (BMI) Report

The BMI Report may be run on your entire patient population but more commonly is run on a template of patients, such as children between the ages of 8 and 12 or active members of your diabetes registry. You may also want to calculate the mean BMI for certain age groups in your population to compare with the mean BMI of other populations or to track community interventions over time.

To produce the BMI Report, begin by saving the active patients in your diabetes registry in a Fileman Search Template.

1. Saving active registry patients in a template

```
What is the Subject of your search?  REGISTER

Register:  IHS Diabetes
```
(Note: Or enter the name of your register.)

```
Status:  Active

Attribute:  <ENTER>

Q-Man Output Options:  Select #4 to save Active Register Patients in a
Fileman Search Template.
```
(Note: Name the template beginning with your initials, e.g. XYZ ACTIVE REGISTER PATIENTS.)

2. Run the BMI Report from the PCC Management Reports menu option, BMI.

```
MAN     PCC Management Reports ...
      BMI     Body Mass Index Reports ...
            OOPT   Risk for Overweight Prevalence Report


Select Body Mass Index Reports Option: OOPT  Risk for Overweight Prevalence
Report

                *****  OVERWEIGHT/OBESITY PREVALENCE REPORT  *****


     Select one of the following:

          S         Search Template of Patients
          P         Search All Patients

   Select List : Search Template of Patients

Enter Patient SEARCH TEMPLATE name: XYZ DM REGISTER PTS
```
(Note: Enter the name of the saved search template of patients.)

```
Enter As of Date:  1/1/2001  (JAN 01, 2001)
```
(Note: The BMI Report may be run for the same template of patients with different dates in order to track the impact of intervention programs.)

```
     Select one of the following:

          E         Each Age in Years listed separately
          G         Age Groups listed

Do you want to see the report with: E// G  Age Groups listed
The Age Groups to be used are currently defined as:

2 - 4
5 - 14
15 - 19
20 - 24
25 - 44
45 - 64
65 - 74

Do you wish to modify these age groups? N// YES
```
(Note: The default age groups may be used or may be changed as desired.)

```
Enter the starting age of the first age group:  (2-74): 2
Enter the starting age of the next age group:  (2-74): 15
Enter the starting age of the next age group:  (2-74): 25
Enter the starting age of the next age group:  (2-74): 35
Enter the starting age of the next age group:  (2-74): 45
Enter the starting age of the next age group:  (2-74): 55
Enter the starting age of the next age group:  (2-74): 65
Enter the starting age of the next age group:  (2-74):  <ENTER>
Enter the highest age for the last group:  (2-74):  <ENTER>

The Age Groups to be used are currently defined as:

2 - 14
15 - 24
25 - 34
35 - 44
45 - 54
55 - 64
65 - 74

Do you wish to modify these age groups? N// <ENTER>

     Select one of the following:

          M         Males
          F         Females
          B         Both

Do you want the report run for: B// Both

Do you wish to include ONLY Indian/Alaska Native Beneficiaries? N// YES
DEVICE: HOME// Printer Number or Name
```

Level II Workshops

Level II Workshop

GPRA +: What Does the Diabetes Data Show?

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Purpose

To describe GPRA + software and provide information on the Government Performance and Results Act (GPRA) diabetes indicators.

GPRA

GPRA requires federal agencies to demonstrate that they are using their funds effectively to meet the agencies' missions. The law requires agencies, including the Indian Health Service (IHS), to establish a five-year Strategic Plan and to submit Annual Performance Plans and Reports with their budget requests. The Strategic Plan describes the long-term goals of the IHS and the Annual Performance Plan describes how the IHS intends to accomplish those goals with their annual budget. Thus, the Annual Performance Plan contains specific performance measures, or *indicators*, for a one-year period. The Annual Performance Report then describes how the agency measured up against the performance targets set in the Annual Performance Plan.

The IHS has established a GPRA Coordinating Committee to guide the agency's Annual Performance Plan development, implementation, and reporting. The Committee is coordinated through the IHS Planning and Evaluation office and consists of multi-disciplinary representatives from the Service Unit, Area, and Headquarters offices. In particular, the Committee is responsible for defining the GPRA clinical indicators.

GPRA +

GPRA + is a Resource and Patient Management System (RPMS) software application that provides local sites and Areas with a straightforward way to produce and review RPMS data for the clinical GPRA indicators. It is a tool that is intended to eliminate the need for manual chart audits when evaluating and reporting clinical GPRA indicators. GPRA + ensures that *comparable* data is generated in a timely manner throughout all facilities that use GPRA +.

In GPRA +, the indicator definitions are translated into RPMS programming code to help you determine which RPMS fields to look at and what values to look for to fit the definitions. GPRA + can also look in multiple RPMS packages for any code that relates to a particular indicator. To use GPRA +, your site must run RPMS because GPRA + relies on data fields that are within the structure of RPMS. It also relies upon pre-defined taxonomies to find data items in the Patient Care Component (PCC) to determine if a patient meets the indicator criteria.

The following is a list of some of the indicators contained in GPRA +:

- 1: Diabetes
- 1B: Historical national diabetes prevalence rates
- 2A-C: Diabetes – Glycemic control
- 3A-C: Diabetes – Blood pressure control
- 4A-C: Diabetes – Dyslipidemia assessment
- 5A-C: Diabetes – Nephropathy assessment
- 6-6A: Women's health – Pap smears, Reduce cervical cancer mortality
- 7: Women's health – Mammograms, Reduce breast cancer mortality
- 8: Child health – Well child visits
- 12: Oral health – Access to dental service
- 13: Oral health – Dental sealants
- 14: Oral health – Improve oral health status of patients with diabetes
- 22: Public health nursing
- 24: Adult immunizations
- 29: Obesity
- 30: Tobacco use and exposure to second hand smoke
- A: Mental health
- B: Colorectal cancer – Reduce colorectal cancer mortality
- C: Diet and exercise education
- D: Diabetic eye exams

GPRA + is designed to run reports for *all* indicators, *some* indicators, or *one individual* indicator. The software will also allow you to choose the time frame and the facility or community for your report. In addition, GPRA + allows you to display the data in different manners: Gender, age, denominator (if more than one), numerator (if more than one), and percentage change from baseline and previous years.

GPRA indicators for diabetes

Although the Administration and Congress have directed all agencies to participate in GPRA, they have given each agency the freedom to determine areas of importance. They also allow each agency to develop data tracking plans and set data goals. This process allows health care providers to provide input in the GPRA goals.

The following table provides information on select diabetes indicators. You can find detailed information on GPRA + and the indicators at the IHS website at www.ihs.gov/CIO/gpraplus.

Table 1. Diabetes group indicators for GPRA +

Indicator	Indication and Target Goal for Fiscal Year 2002	Denominator	Numerator	Prevalence Changes
Indicator 1: Diabetes Area and age-specific prevalence rates for the American Indian and Alaska Native (AI/AN) population	Indication: Part of monitoring progress of ongoing efforts in the treatment and prevention of diabetes Target Goal: Maintain database	All active users	Numerator 1A: Anyone diagnosed with diabetes (250.00—250.93) before the end of the period Numerator 1B: Anyone diagnosed with diabetes (250.00—250.93) in the year prior to the end of the time period	Prevalence changes 1990—1998: 68% increase in 15–19 year olds 47% increase in 20–24 year olds 50% increase in 25–34 year olds Overall increase for AI/AN <35 years of age: 51% increase
Indicator 2: Glycemic control Increase the proportion of IHS, tribal, and urban (I/T/U) clients with diagnosed diabetes that have improved their glycemic control	Indication: Indicator directed at reducing diabetic complications by improving glycemic control in I/T/U clients diagnosed with diabetes Target Goal: Improve from FY 01 level of 30%	Denominator 2A: All active users diagnosed with diabetes Denominator 2B: All active users diagnosed with diabetes *plus* the patient must have had two visits in the past year and the first ever diabetes diagnosis (250.0—250.93) must have occurred less than one year prior to the end of the time period Denominator 2B: All active users diagnosed with diabetes *plus* the patient must have had at least two visits with a primary care provider, the patient must be 19 years old or older at the beginning of the time period, and the patient must never have had a creatinine >5	Numerator 2A: Number of patients with a A1c ≤7 or with a mean of the last three glucose values less than or equal to 150 Numerator 2B: Number of patients with A1c ≥9.5 or mean of the last three glucose values ≥225 Numerator 2C: Number of patients with undetermined A1c and more than three glucose values in the year prior to the end of the time period Numerator 2D: Number of patients with an A1c documented in the year prior to the end of the time period NOTE: This will count all patients who had a A1c documented whether or not the test had a valid result	GPRA + for Numerator 2A: – Denominator 2A: 27% – Denominator 2B: 29% – Denominator 2C: 30% (same as Program Performance for FY 01) GPRA+ for Numerator 2D: – Denominator 2A: 61% – Denominator 2B: 69% – Denominator 2C: 91%

Indicator	Indication and Target Goal for Fiscal Year 2002	Denominator	Numerator	Prevalence Changes
Indicator 3: Blood pressure control Increase the proportion of I/T/U clients with diagnosed diabetes and hypertension that have achieved diabetic blood pressure control standards	Indication: Indicator directed at reducing diabetic complications by improving blood pressure control in I/T/U clients diagnosed with diabetes who have achieved blood pressure control Target Goal: Maintain at FY 01 level of 41%	See denominators for Indicator 2	Numerator 3A: Number of patients with controlled blood pressure, mean systolic value is <130 *and* mean diastolic value is <80 Numerator 3B: Number of patients with uncontrolled blood pressure. Mean systolic value ≥130 and mean diastolic value ≥80 Numerator 3C: Number of patients with undetermined blood pressure. Patients with less than three blood pressures documented in the year prior to the end of the time period	GPRA + results for good blood pressure control: – Denominator 3A: 36% – Denominator 3B: 41% (same as Program Performance for FY 01) – Denominator 3C: 47%
Indicator 4: Dyslipidemia assessment Increase the proportion of I/T/U clients with diagnosed diabetes who have been assessed for dyslipidemia	Indication: Indicator directed at reducing diabetic complications by lowering the serum cholesterol in I/T/U clients diagnosed with diabetes Target Goal: Improve from FY 01 (60%)	See denominators for Indicator 2	Numerator 4A: Number of patients with an LDL *plus* there is evidence of having a lipid profile *or* having an LDL and HDL and Triglyceride (TG; all three) *plus* there is evidence of having an LDL only *plus* there is evidence of having an LDL and HDL *or* TG Numerator 4B: Number of patients with LDL results Numerator 4C: Number of patients with LDL results <130	GPRA + results for Numerator 4A: – Denominator 4A: 41% – Denominator 4B: 49% – Denominator 4C: 60% GPRA + results for Numerator 4C: – Denominator 4A: 36% (of 41%) – Denominator 4B: 43% (of 49%) – Denominator 4C: 52% (of 60%)
Indicator 5: Nephropathy assessment Increase the proportion of I/T/U clients with diagnosed diabetes who have been assessed for nephropathy	Indication: Indicator directed at reducing diabetic complications, such as End Stage Kidney Disease or diabetic kidney disease in clients diagnosed with diabetes Target Goal: Improve from FY 01 (54%)	See denominators for Indicator 2	Numerator includes patients who have a positive urine dipstick protein value *or* have had a microalbuminuria test done Results of microalbuminuria test can be positive or negative	Using GPRA + (at one site without microalbuminuria screening): – Denominator 5A: 26% – Denominator 5B: 31% – Denominator 5C: 36%

Indicator	Indication and Target Goal for Fiscal Year 2002	Denominator	Numerator	Prevalence Changes
Upcoming indicator for FY 03 for a limited number of sites: Diabetic retinopathy screening Increase the proportion of I/T/U clients with diagnosed diabetes who have been assessed for retinopathy	Indication: Indicator directed at reducing diabetic complications by screening for eye disease in I/T/U clients diagnosed with diabetes Target Goal: To be determined	To be determined	To be determined	

Level II Workshop

PCC +

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Purpose
To provide an overview of PCC + and its benefits, barriers, and solutions.

Background on PCC +
PCC + is a software application that provides a connection between the Resource and Patient Management System (RPMS) and Microsoft Word to yield a variety of real time documents, such as customized encounter forms, health summaries, patient education materials, claims forms, outguides management reports, and order entry forms. The software application, designed for use at the local level, enables Patient Care Component (PCC) users to utilize a set of standard templates for each patient visit. These templates are designed to improve quality of care, as well as data and billing integrity. In addition, users can also build a customized encounter form in real time for each patient visit.

PCC + was developed to help respond to changes in medical practice and local needs. The software can increase data capture, thereby encouraging you to use clinical practice guidelines and decreasing burden on data entry staff.

Benefits, barriers, and solutions associated with PCC +
The following are some key points and benefits of PCC +:

- Operates without the need to change the PCC code
- Integrates clinical and billing functions into one form
- Requires multi-departmental collaboration for successful implementation
- Provides two levels of customization:
  - Form type (e.g., diabetes, ambulatory, dental, etc.)
  - Site-specific (i.e., based on the individual characteristics of the clinic, provider, and patients)
- Generates the form in real time on a laser printer
- Standardizes care through built-in clinical protocols
- Takes advantage of new technology (e.g., Windows, Microsoft Word, laser printers, internet)

- Includes a variety of form templates (e.g., Ambulatory, Well Child, Podiatry) for site use or customization

Sites using PCC + have experienced many benefits, the most important of which is that PCC + has been a catalyst for change, particularly in the areas of improved workflow, improved business processes, and improved data capture and quality. Other benefits include:

- Increased data entry quality and productivity due to improved completeness and legibility
- Elimination or reduction of data entry lag time
- Improved coding and problem documentation
- Enhanced charge capture
- Improved Problem List maintenance and Purpose of Visit documentation

Several barriers and problems associated with using PCC + exist:

- Implementation and support is much more complex than the average PCC application
- Staff at some sites do not have the time to design custom documents for their site
- PCC + produces only an original document with no copies
- You will have to change the way you do business to take advantage of the technology

To address some of these barriers, we have implemented the following solutions:

- Training network: Information Technology Support Center, Area sites, and local sites
- Remote installation and support
- Automated installation and validation
- Pre-configuration of print servers via drive image
- Special training and help desk software for the support staff
- Alpha tests have resolved issues regarding documentation, training, and system reliability

How does PCC + work?

PCC + generates customized reports and documents through a mail merge process between RPMS and Microsoft Word. The mail merge combines information from your individual clinical data files (i.e., RPMS), population clinical data files (i.e., where you store gender- and age-specific clinical reminders), template files (i.e., template forms for specific clinics and clinical diagnoses), and demographic files. Figure 1 displays the different types of forms that you can develop and the data that you can include using PCC +. Figure 2 illustrates the process of merging the RPMS data into a Microsoft Word mail merge document.

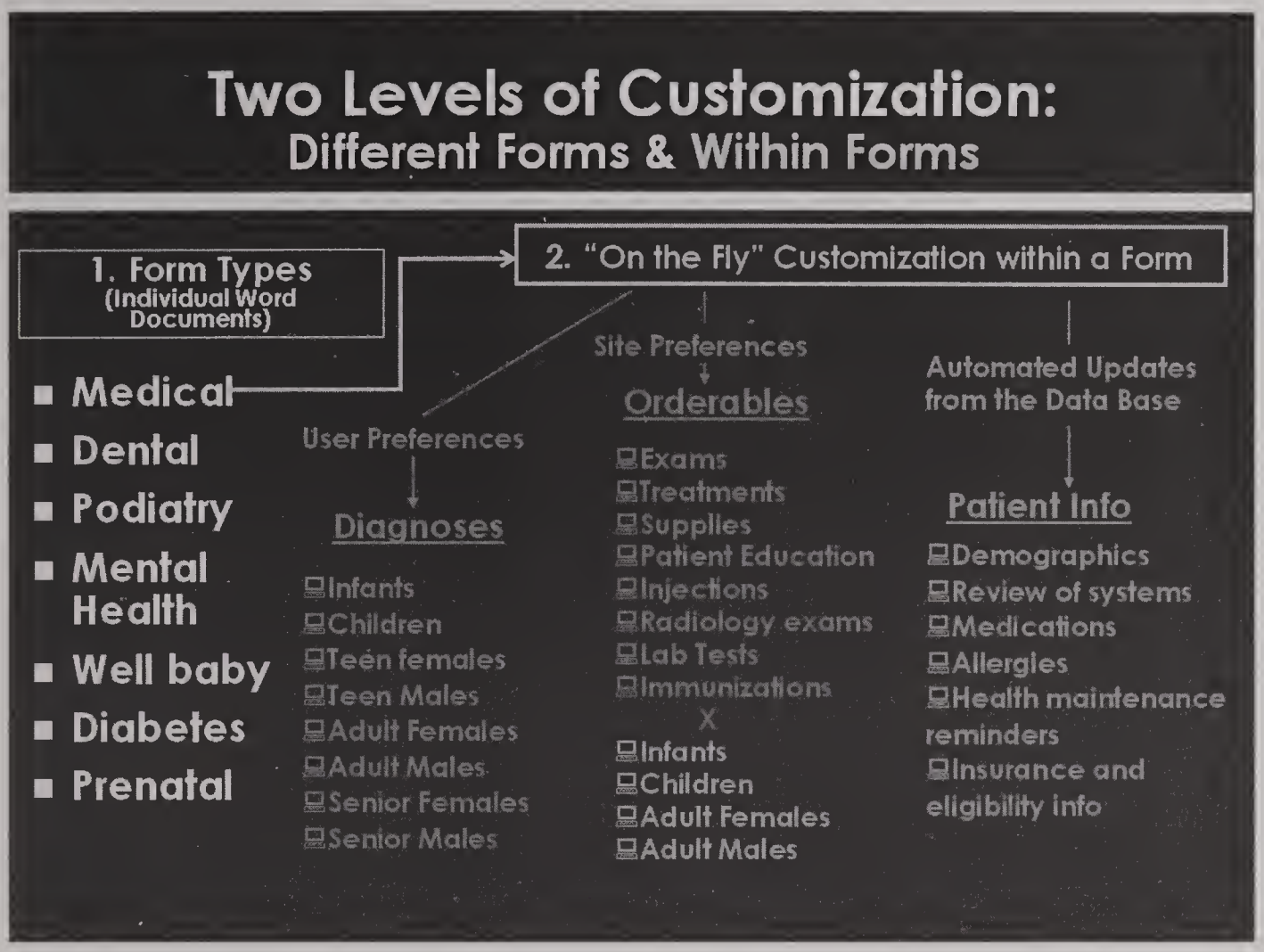

Figure 1. Types of forms that you can develop and data that you can include using PCC +

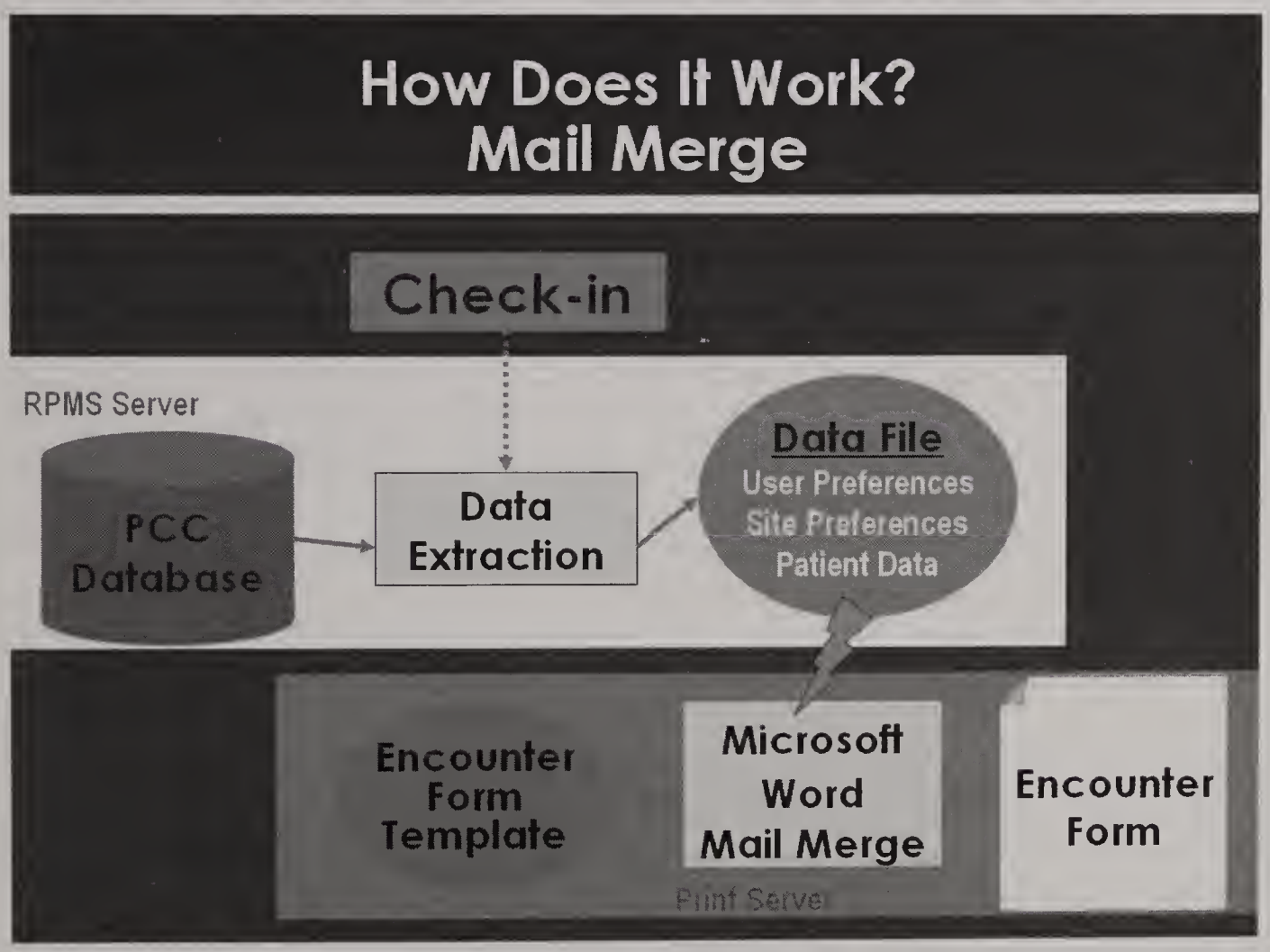

Figure 2. Schematic of the document creation process

Support for PCC +

The PCC + website, located at www.ihs.gov/CIO/PCCPlus/pccplus-intro-resources.asp, includes introductory information on PCC +, including orientation and technical presentations; orientation and activity calendars; planning information, such as technical and system requirements, site evaluation surveys, and metrics planning; templates; and technical manuals.

Level II Workshop

RPMS Data Quality Issues and Diabetes Measures

Stanley Griffith, MD
Information Technology Support Center
Indian Health Service

Michael Gomez
Indian Health Performance Evaluation System
Indian Health Service

Purpose

To describe the most recent studies that investigated the agreement between data within the Indian Health Service (IHS) Resource and Patient Management System (RPMS) and in medical charts; and to review the activities of the IHS to improve RPMS data quality.

Blood pressure control

For blood pressure control, we examined 1,000 patients at five diverse sites. We compared data in RPMS with data in the written medical chart. The RPMS data from IHS Headquarters indicated that *40.5%* of patients' blood pressures were "in control." The data from the medical charts indicated that *40.4%* of patients' blood pressures were "in control"—a one-person difference between the data in RPMS and in the medical charts. The data needed for this measure are highly accurate.

This data in RPMS appear to be so accurate for at least two reasons. First, the data are accurate because blood pressure data are reliably entered into RPMS. Second, the measurement that we examined depends on a statistical manipulation of multiple service points. For example, if we examine ten blood pressure measurements and omit three random measurements, we still have multiple service points upon which we can perform our analysis. We would not expect that losing three measurements would affect the results of our analysis because the median of seven measurements should still be close to the median of ten measurements. Furthermore, if we perform a measurement that does not vary much week-to-week, such as weight or height, and we miss several measurements, our analysis should not be greatly affected. This is indeed what we learned: If a measurement depends on a statistical manipulation and has multiple service points, the results are more likely to be accurate.

HIV diagnoses

In a study that was published in the June 2002 issue of *IHS Provider*, we conducted an ICD-9 search in RPMS for HIV diagnoses at multiple Service Units in one state and IHS Area. We matched RPMS patient hits with the state HIV registry. If we could not match a patient listed as having HIV in RPMS with a patient listed on the state HIV registry, we conducted a manual chart review. If we still could not confirm that the patient had HIV, we conducted a more intensive electronic Patient Care Component (PCC) search and chart review. In the study, we

found 100 patients who had an HIV diagnosis in RPMS, but were able to confirm only 82 diagnoses with the state HIV registry. We were able to make three additional confirmations when we reviewed the electronic data and found confirming laboratory results. The 15 false-positives were due to miscoding, inaccurate provider recording, data entry errors, missing charts, and patients who inaccurately reported a history of HIV to the provider who then appropriately recorded the information in the medical chart.

We learned that we must be cognizant of the prevalence of a condition when using RPMS to screen for that condition—similar to when we use screening tests in clinical practice. If a test that is highly specific and sensitive—99% specific and 99% sensitive— is used in a population that has a low prevalence for the screened condition (e.g., 1% prevalence rate), statistically we would expect a false positive rate of 50%. For example, for 20 identified cases, 10 would actually have the condition and 10 would not. In contrast, if we used the same test in a population in which there was a 30% prevalence rate, we would expect a 2% false positive rate. For example, out of 304 identified cases, 297 would actually have the condition and 7 would not. Since HIV fortunately has a relatively low prevalence in this population, we expected and actually found a moderate false-positive rate of 15%.

Invasive cervical cancer

In an unpublished study, we conducted an ICD-9 search for invasive cervical cancer at multiple sites in one IHS Area. We asked if PCC could make the fine distinction between invasive cervical cancer and other conditions, such as noninvasive cervical cancer, pre-malignant cervical disease, and other closely related conditions. Invasive cervical cancer has a very low prevalence rate in this population compared to the other related conditions, so we expected a high false positive rate. In other words, we expected only one person to actually have invasive cervical cancer for numerous identified cases. Our results confirmed this; we found a 91% false positive rate. But, we also found that the majority of these false positives had some of the previously mentioned conditions that are related to invasive cervical cancer, such as localized cancer and pre-cancerous conditions.

Using ICD-9 codes alone is not sufficient

Using ICD-9 codes is very helpful when trying to narrow down which cases will need a manual review or a closer examination of the electronic record. However, using the ICD-9 search alone to identify cases is not always sufficient. Furthermore, ICD-9 codes may work well when looking for cases in which the prevalence of the screened condition is high, such as diabetes. But trying to use *ICD-9 code searches alone would not work well* in other situations, such as:

- Distinguishing between type 1 and type 2 diabetes
- Looking for conditions or diseases with a low prevalence relative to a closely related, much more prevalent condition
- Determining how many patients have a relatively rare, special complication or condition

Activities to improve RPMS data quality

Indian Health Performance Evaluation System (IHPES)

IHPES supports the ORYX hospital standards and Government Performance and Results Act (GPRA) data quality issues. Primary responsibilities of IHPES include:

- Preparing formal classroom instruction
- Improving applications to examine the quality, integrity, and completeness of data
- Working on the reporting tools that are used via the internet to help sites monitor the timeliness and coding of their data
- Expanding these activities to support other program requirements

IHPES also works to improve ORYX hospital accreditation issues and issues related to GPRA. Both are performance measurement requirements, but ORYX supports hospital accreditation standards, whereas GPRA is a performance measurement that applies to all Federal agencies. The goal of IHPES is to support both performance measurement activities by standardizing the data for both ORYX and GPRA.

Our accreditation customers, which include 42 out of 49 hospitals in the IHS, use the IHPES system, giving them access to tools on the internet that provide information on the PCC export files that have been received by the national program. This information includes methods for data coding, validation that local export files were received, and timeliness of data. Access to this information is important for helping us identify the bottlenecks, errors, and delays in transmitted data from local sites to the national level.

Data quality assessment programs

We have developed a data quality assessment program that is installed on laptops for use during site assessments. The program allows you to download clinically relevant information that has been received at the IHS National Diabetes Program from local sites. You can then use the application to review charts at local sites and compare it with data that have been received at the national level. The program can provide you with reports that summarize what the assessment has uncovered and outline recommendations and opportunities for improvement at the local level. If, for example, you are comparing immunization data that have been received at the national level to the information that is documented in the medical charts at the local level, the program can also generate a list of patients who are not current on their immunizations.

Future directions

- Revised PCC export record with additional fields
- Data warehouse activity
- A clinical measure designed to look at the completeness, timeliness, and accuracy of RPMS PCC clinical data added to GPRA

Level III Workshops

Level III Workshop

Field Presentations: How It Works in the Real World

Purpose
To describe various programs and strategies that have been used by different tribes to establish diabetes programs and data systems.

Chris Hansom, RN, CDE
Lake County Tribal Health Consortium, Inc.

Lake County Diabetes Program
When the Lake County Diabetes Program began, we gathered input from the community on what activities the community wanted and needed. This input drove the development of our community prevention activities, which included nutrition counseling, healthy luncheons, healthy picnics and barbeques, cooking classes, recipe testing, and shopping trips.

In response to the fact that our community's children and teenagers were overweight, had high blood sugar, or had a family history of diabetes, several of our diabetes program activities focused on diabetes prevention in youth. The youth activities included hiking; fossil hunts; nature walks; medicinal plant sessions; and cultural activities, such as basket weaving and rock painting. Thus far, we have organized two Native American Olympics, during which approximately 500 people attended. Our activities and competitions include backwards run, 50-yard dash, sack races, volleyball, softball, tug of war, sidewalk art, and grass games.

Our diabetes program also implemented a Weight Watchers Program in November 2001 in response to the interest of our community members in the highly successful weight loss program. To implement the Weight Watchers Program, we used funds from the *Special Diabetes Program for Indians*, obtained the support of the local casino which pays for its employees to participate in the program, and obtained a Local Incentive Award grant.

The goals of our program were simple, realistic, and included weight loss, improved blood glucose, improved A1c levels, improved lipid levels, and increased exercise. Our program has 44 regular members. Since November 2001, our participants have lost a total of 2,000 pounds.

Pam Knispel
Lake County Tribal Health Consortium, Inc.

Lake County Diabetes Program—Community Gardens

The Lake County Diabetes Program developed a community garden program to stimulate community interest in healthy eating, social interaction, exercise, and community service. The goals of the community garden were to: 1) improve the health of the Native population through healthy eating and nutrition awareness, and 2) serve as an education resource.

To start the project, we approached the Tribal Board of Directors to obtain their support. We were able to obtain a grant for one acre of land for the project. Once we had obtained the tribal resolution and the land grant, we took soil samples to a pharmacology lab for analysis. This would help us in our garden planning by telling us about soil deficiencies, pH levels, nutrient values, and saturation rates. We then purchased our seed, plants, fertilizers, garden tools, and irrigation supplies. When we began the garden project, we had a $2,500 budget. Our estimate, however, was that it would cost $9,600 to fund the garden fully. With the assistance of the tribal community and our neighbors, our project obtained over $6,000 in in-kind goods and services.

As a result of the community garden's success, every reservation in Lake County signed up for a community garden in 2002. The gardens were collectively launched on Earth Day. Since June 6, 2002, the gardens have been producing fruits and vegetables, which are delivered to people with diabetes. In October, we will begin a series of canning and food preservation classes on every reservation. Other activities include community pantries and garden tours. For first time in Lake County, every reservation has entered their produce in the county fair. The most important outcome of the gardens, however, is that the gardens have provided hundreds of tribal members on every reservation in Lake County with access to fruits and vegetables.

To expand the activities of our community gardens, we have proposed the development of a hothouse where tribal members can grow medicinal plants and produce for both the summer and winter seasons. We have also proposed to build a greenhouse near our clinic, where patients can wait for their appointments. The greenhouse will include a fish pond, water fountain, plants, and benches, providing patients with a nurturing environment where they can spend time during their clinic visits.

Audrey Lynch
Diabetes Center of Excellence
Phoenix Indian Medical Center

The Phoenix Indian Medical Center Diabetes Register

The Phoenix Indian Medical Center (PIMC) tracks over 10,000 patients in its diabetes registry. To help track these patients, each patient is assigned a status code. Patients visit the PIMC for different reasons and at different frequencies, such as regularly scheduled visits, specialty visits, laboratory visits, emergency visits, one-time visits, and seasonal visits. Understanding the various types of visits helps the PIMC define patient status in our diabetes registry. The following is a list of each patient status and its definition as assigned at the PIMC:

- Active: Last visit was less than three years ago
- Inactive: Last visit was more than three years
- Transient: The patient receives primary care elsewhere
- Deceased: Date of death is listed in Patient Care Component (PCC) or a family member informs staff of the death
- Non-Indian Health Service (IHS): The patient is not eligible for IHS benefits
- Lost to follow-up: Unable to review patients' records
- Unreviewed: An assessment is needed

To maintain and update our diabetes registry, which tracks a large number of patients, we have established an internal system that allows us to use our diabetes registry for improved clinic management. The following is an outline of our maintenance system:

- Step One: Create a template for each status through the Diabetes Management System (DMS) report generator.
- Step Two: Identify patients who have been recently diagnosed with diabetes. We use a Q-Man query template to find patients with a first-time diagnosis of diabetes.
- Step Three: Compare patients found in the "newly diagnosed" query with patients who are in a template that searches for patients whom we know have been previously miscoded or misdiagnosed with diabetes. We then filter out the patients who have been previously diagnosed so they will be excluded from our diabetes registry.
- Step Four: Add new patients to the diabetes registry. We use the Case Management System to add new patients so that we can add patients with the status of "unreviewed."

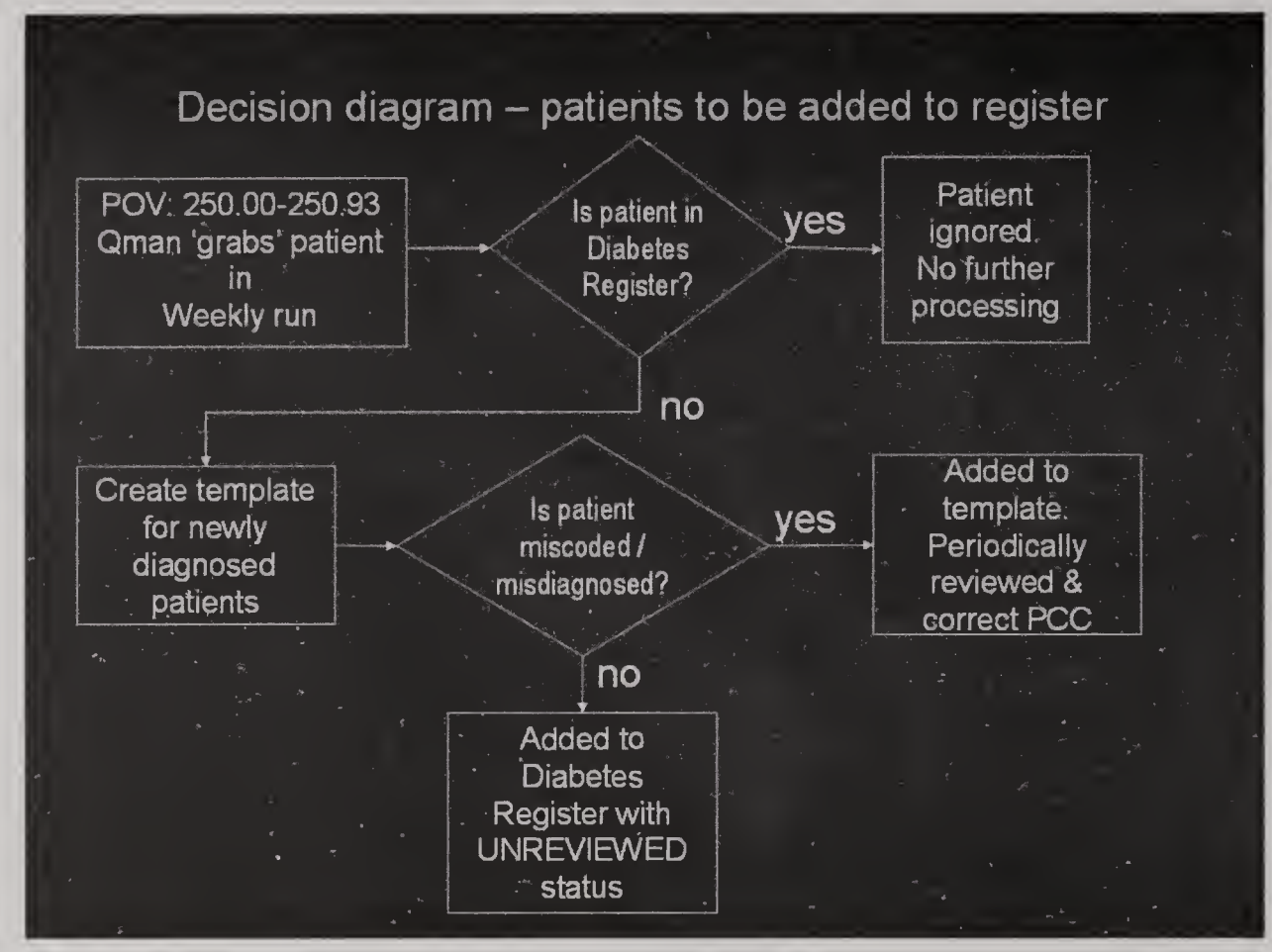

Figure 1. The first four steps in maintaining and updating the PIMC diabetes registry

- Step five: Conduct chart reviews.
- Step six: Search for all people who have not had a visit in the last three years and change their status to "inactive."
- Step seven: Search for all "active" patients and change their status accordingly.
- Step eight: Classify eligibility. Identify patients who are ineligible for IHS care and change their status to "Non-IHS."
- Step nine: Conduct a subjective review to classify patients, especially patients who are "intransient" or "lost to follow-up." Case managers use their clinical experience to evaluate and classify these patients on an individual basis. Deceased patients are automatically updated by DMS or updated when a family member notifies staff of deceased status.

The PIMC has identified several weaknesses in these methods. For example, subjective criteria are used inconsistently, and therefore the "active" group likely represents many different types of patients. Also, because we have not developed procedures to correct large volumes of PCC data effectively, some of our methods create redundant work.

Joseph Gladstone, MPH
Tohono O'odham Department of Human Services

Designing a Diabetes Data Collection and Evaluation System for Planning Health Education Strategies

The Tohono O'odham Nation is in the process of building a system called DITTO, the Diabetes Information Tracking for Tohono O'odham. The objectives for DITTO are to:

- Establish and determine diabetes prevalence within the Tohono O'odham Nation by age, gender, geography, etc. (i.e., other information we have not thought of yet).
- Confirm IHS Service Unit data.
- Design community-wide diabetes screening to capture data from those outside of the IHS database.
- Identify community knowledge, attitudes, and behaviors about diabetes by age, gender, geography, etc.
- Design automated client management system for both individuals and groups.
- Ensure that database is exportable to statistical packages, such as SPSS, SAS, EpiInfo, and the Resource and Patient Management System (RPMS).
- Ensure that data are usable for program administrators, stakeholders, and future diabetes program staff and stakeholders.
- Ensure that the database is flexible, expandable, and manageable to adjust for unforeseeable change in technology and program needs.
- Ensure that the data system correlates program activities with future diabetes prevalence.

If designed and used properly, DITTO will become a valuable resource for designing locally appropriate intervention strategies. The Tohono O'odham Nation plans to use the data that are collected from DITTO for the following purposes:

- Program planning
  - Set program goals, such as those outlined by the community, Healthy People 2010, or the Government Performance and Results Act (GPRA)
- Develop intervention strategies
  - Manage and maximize resources, including materials, staff, and money
  - Process evaluation: Is this plan working?
- Plan programs
  - Set program goals
  - Design intervention strategies
- Forecasting

  - When you have enough data, you can ask questions like, "What might happen if we implement plan A? What might happen if we instead implement plans B or C?"
  - Evaluate your options using statistics and data
- Report progress
  - Report on the activities that were delivered, the clients that were served, the outcomes, and the effect of the programs
  - Show how the money given to the program actually created change in diabetes prevalence in Indian Country

Level III Workshop

Using DMS and Excel to Analyze the Diabetes Audit

Jennifer Olson, MS
Western Tribal Diabetes Project
Northwest Portland Area Indian Health Board

Purpose

To describe how to track information on patients with diabetes and use this information to improve quality of care.

Using Excel reports to help improve quality of care

Providers often want to know how they can use data from the Indian Health Service (IHS) Diabetes Care and Outcomes Audit (diabetes audit) to help them improve the quality of care for people with diabetes. One way to help you apply the information in the diabetes audit to improve care and health outcomes is to place your audit results into Microsoft Excel. The Western Tribal Diabetes Project at the Northwest Portland Area Indian Health Board has developed a pre-formatted Excel spreadsheet to generate an automated health status report using the data from the diabetes audit. Using this pre-formatted Excel spreadsheet, you can generate colorful graphs that are easy to read and understand, allowing you to better communicate your data.

Placing diabetes audit results into a pre-formatted Excel spreadsheet

You can print a diabetes audit report from the Diabetes Management System (DMS) or from EpiInfo (see Figure 1). This cumulative diabetes audit report is concise and provides data on the IHS Diabetes Standards of Care, but it does not produce graphs and charts that will help you illustrate your data. By placing the data into the pre-formatted Excel spreadsheet, however, you will be able to produce graphs and charts for your data.

When you are in the pre-formatted Excel spreadsheet, you can manually enter or electronically import your diabetes audit data into the Excel spreadsheet. Once you have entered or imported all of your data, Excel will produce a 13-page report that includes charts and graphs of your diabetes audit data. The Excel report also contains narratives that provide background information and describe the data. The report also allows you to review data over four different time periods (called the "Over Time" report in Excel) or over several different sites.

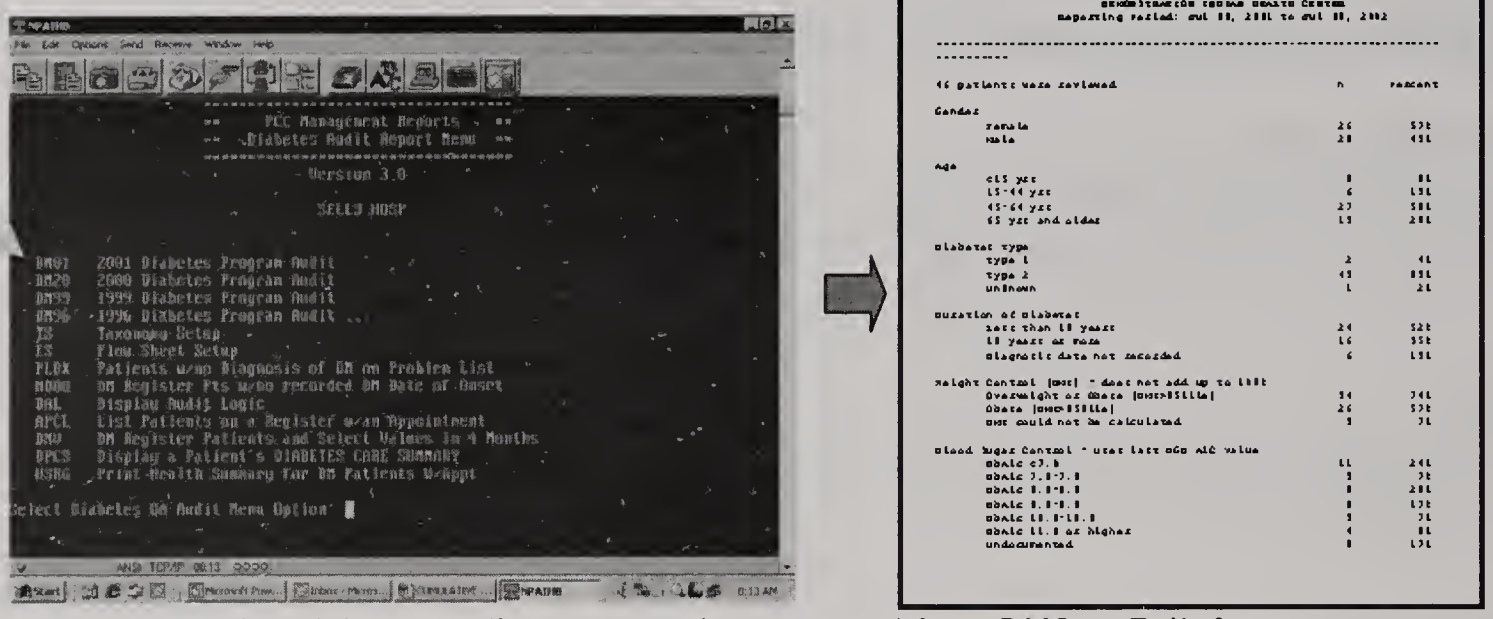

Figure 1. A cumulative diabetes audit report can be generated from DMS or EpiInfo

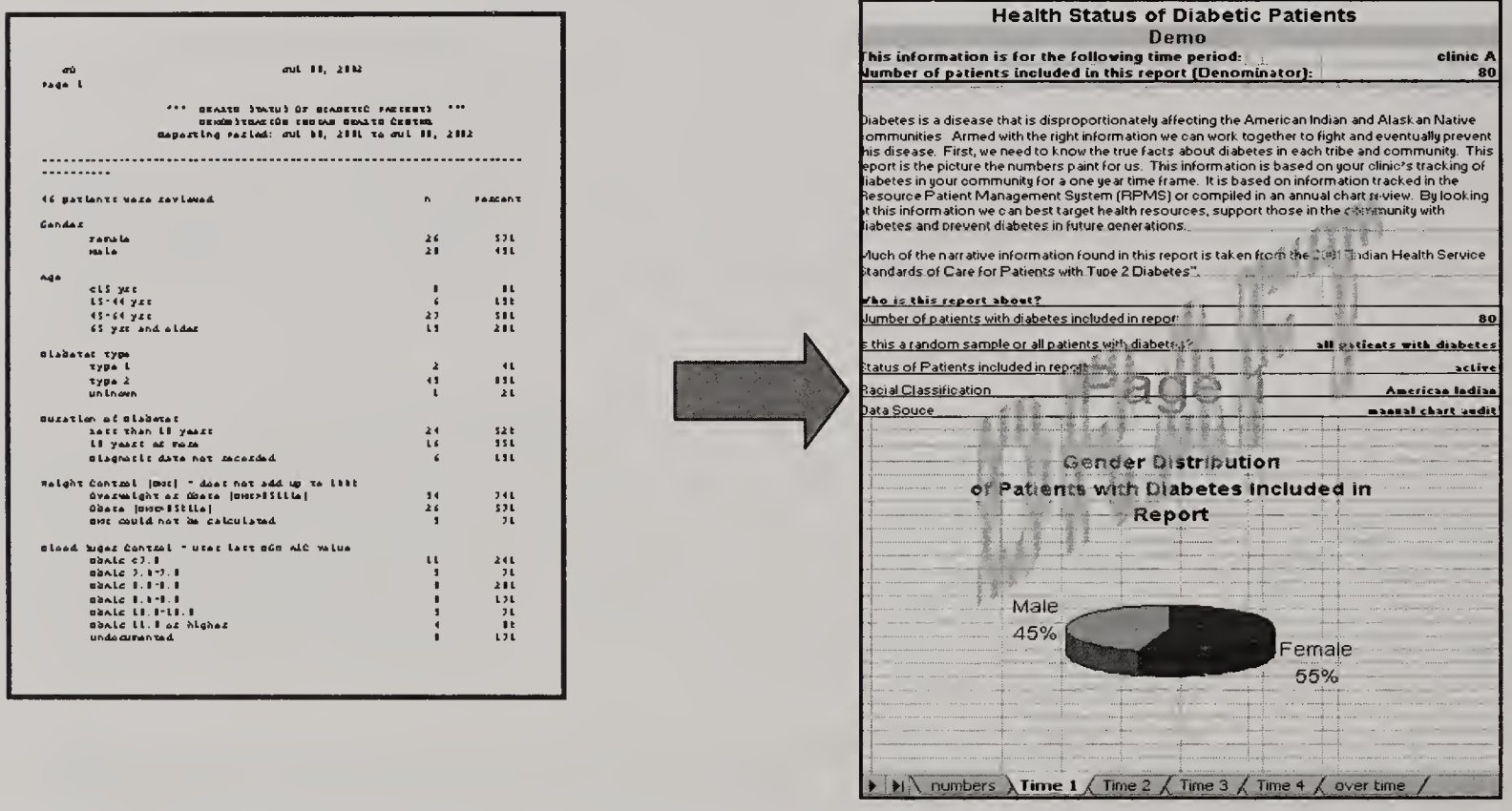
Health Status of Diabetic Patients
Demo
This information is for the following time period:
clinic A
Number of patients included in this report (Denominator):
80
Diabetes is a disease that is disproportionately affecting the American Indian and Alaska Native communities. Armed with the right information we can work together to fight and eventually prevent this disease. First, we need to know the true facts about diabetes in each tribe and community. This report is the picture the numbers paint for us. This information is based on your clinic's tracking of diabetes in your community for a one year time frame. It is based on information tracked in the Resource Patient Management System (RPMS) or compiled in an annual chart review. By looking at this information we can best target health resources, support those in the community with diabetes and prevent diabetes in future generations.
Much of the narrative information found in this report is taken from the "Indian Health Service Standards of Care for Patients with Type 2 Diabetes".
Who is this report about?
Number of patients with diabetes included in report
80
Is this a random sample or all patients with diabetes?
all patients with diabetes
Status of Patients included in report
active
Racial Classification
American Indian
Data Souce
manual chart audit
Gender Distribution
of Patients with Diabetes included in
Report
Male
45%
Female
55%
numbers
Time 1
Time 2
Time 3
Time 4
over time

Figure 2. A health status report can be generated in Excel from the cumulative diabetes audit report

How can you use the Excel report?

You can share the report with communities, tribal health boards, and other stakeholders to show them how their work has helped improve diabetes care. For example, you can include the graphs from the report in PowerPoint presentations or overhead presentations. You can also use the information at group diabetes meetings to show how individual health status may compare to community health status. The report can also be used to illustrate clinical quality improvement activities or to pinpoint areas that can be easily improved.

Your data can also be sorted by provider or by community in either the Resource and Patient Management System (RPMS) or EpiInfo and then entered into Excel to compare performance. The "Over Time" Excel report can be adapted to compare up to four providers or four sites (see Figure 3). You could also focus on improving several indicators over the period of one year. The report can be generated several times during that year and the "Over Time" report can be used to measure progress on improving those indicators (see Figure 4).

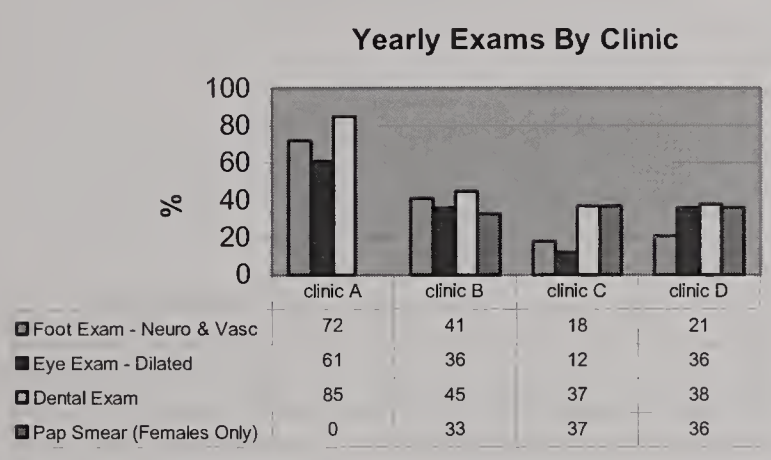

Figure 3. "Over Time" report to compare four providers or sites

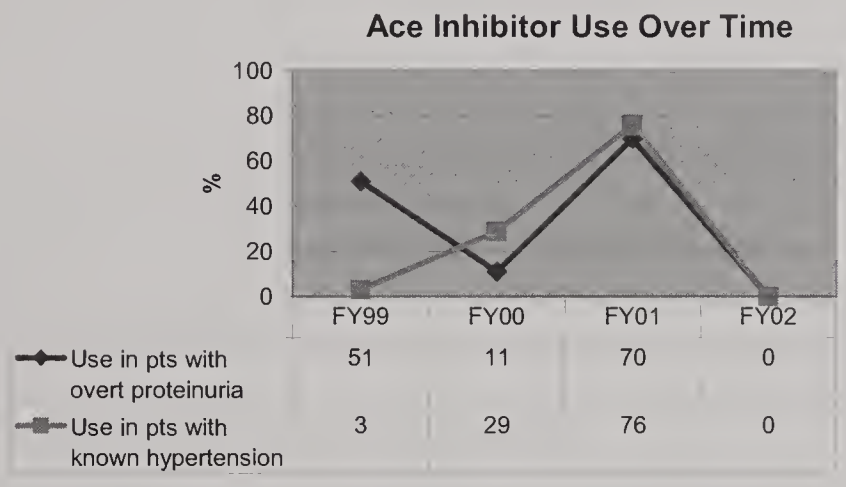

Figure 4. "Over Time" report to measure improvement progress on several indicators

For more information on the pre-formatted Excel spreadsheet or to obtain an electronic template, please contact the Western Tribal Diabetes Project at the Northwest Portland Area Indian Health Board at 503.228.4185.

Numerator and Denominator Workshops

Numerator Workgroup

Cardiovascular Care

Charles Rhodes, MD
Phoenix Area Diabetes Consultant
Indian Health Service

Recommendation #1: Develop a system to ensure electrocardiogram (EKG) reports are entered into the Resource and Patient Management System (RPMS)

When patients are referred to outside providers, EKG reports are often sent directly to the medical records department and are not entered into RPMS. Consequently, the EKG is omitted from the Indian Health Service (IHS) Diabetes Care and Outcomes Audit (diabetes audit) until a manual chart review is conducted at these sites.

The workgroup recommended that if you choose to do an electronic diabetes audit, it may be helpful to supplement the electronic audit with a manual audit. However, because manual audits tend to be time- and staff-intensive, sites may want to review the medical charts for only the patients who show up in RPMS as not having had an EKG.

The workgroup also recommended that sites follow another system, which has been implemented in the California Area. This system involves performing the following steps every time a patient with diabetes visits the clinic: 1) run the health summary the day before the patient's appointment; and 2) review the health summary and highlight areas that the physician needs to address, such as EKGs or immunizations. This system prompts the provider to ask the patient if he or she has received care off-site.

Finally, the workgroup recommended the development of a routing system that requires staff to place a copy of correspondence from specialists, such as cardiologists or eye doctors, in the mail boxes of the diabetes program, data entry department, and medical records department. This will help ensure that EKG reports are entered into RPMS.

Recommendation #2: Track patients with Insulin Resistance Syndrome

Cardiovascular problems can begin before a person is diagnosed with diabetes. People with Insulin Resistance Syndrome (also known as metabolic syndrome or Syndrome X) also have high rates of cardiac events. Most cardiovascular disease is due to diabetes or Insulin Resistance Syndrome. As one workgroup participant stated, "Diabetes is not a risk factor for coronary artery disease, it is coronary artery disease."

The workgroup recommended that sites begin tracking cardiac events, visits to cardiologists, and cardiac rehabilitation for both diabetes patients and patients with Insulin Resistance Syndrome. To help track this data for people with Insulin Resistance Syndrome, sites should consider developing an Insulin Resistance Syndrome registry, much like the diabetes registries already used widely.

The new ICD-9 code for Insulin Resistance Syndrome can be used to code the condition. The American Association of Clinical Endocrinologists (AACE) recently announced that the new code, 277.7, has been approved by the Centers for Disease Control and Prevention. The AACE suggests the following major and minor criteria for Insulin Resistance Syndrome:

- Insulin Resistance Syndrome denotes a constellation of metabolic abnormalities in serum or plasma insulin/glucose level ratios, lipids (triglycerides, LDL cholesterol subtypes and/or HDL cholesterol), uric acid levels, coagulation factor imbalances and vascular physiology.
- Major criteria
  - Insulin resistance (denoted by hyperinsulinemia relative to glucose levels) or acanthosis nigricans
  - Central obesity (waist circumference more than 102 cm for men and more than 88 cm for women)
  - Dyslipidemia (HDL cholesterol less than 45 mg/dl for women, HDL cholesterol less than 35mg/dl for men, or triglycerides greater than 150 mg/dl)
  - Hypertension
  - Impaired fasting glucose or type 2 diabetes
  - Hyperuricemia
- Minor features
  - Hypercoagulability
  - Polycystic ovary syndrome
  - Vascular endothelial dysfunction
  - Microalbuminuria
  - Coronary heart disease

Recommendation #3: Improve methods for capturing data on use of over-the-counter medication and supplies

One site reported that their diabetes audit results indicated that 100% of their patient population did not self-test, and only 1% of the population used aspirin. Both self-testing strips and aspirin are available over-the-counter. Therefore, the information is not picked up by RPMS, and the diabetes audit yielded incorrect data on the use of over-the-counter medication and supplies.

Recommendation #4: Screen patients before they have diabetes

The workgroup recommended that cardiovascular monitoring extend to a larger population of people, namely people who do not have diabetes. People who have conditions, such as obesity, hypertension, dyslipidemia, polycystic ovary syndrome, acanthosis nigricans, and gestational diabetes, should also receive cardiovascular monitoring. In addition, we should be track cardiovascular monitoring and therapy.

Numerator Workgroup

Chronic Kidney Disease

Andrew Narva, MD, FACP, Moderator
Chief Clinical Consultant for Nephrology and Internal Medicine, Albuquerque Area Indian Health Service

Background

Chronic kidney disease is a public health problem. An epidemic of kidney failure exists in the U.S.—not just in American Indian and Alaska Native (AI/AN) communities. However, because the public health community tends to look at populations, it does not necessarily consider chronic kidney disease a public health problem because End-stage Renal Disease (ESRD) affects only one out of a thousand people. Even the Centers for Disease Control and Prevention (CDC) does not employ nephrologists, and their involvement in kidney disease is limited to only their Division of Diabetes Translation.

Although kidney disease is a growing problem in the population as a whole, the burden of the disease is carried disproportionately by minority communities. Incidence rates of ESRD are three to four times higher among African Americans and AI/ANs than among whites. The rates for some AI/AN communities are on the order of 15 to 20 times higher.

The recognition of kidney disease as a public health problem has been marked by several recent developments:

- Healthy People 2010 included a chapter on kidney disease.
- The National Kidney Foundation (NKF) developed a major initiative, called the Kidney Disease Outcomes Quality Initiative (K/DOQI), to establish evidence-based standards of care for people with progressive kidney disease.
- The National Institutes of Health (NIH) established a National Kidney Disease Education Program to increase awareness of chronic kidney disease and to improve care.

As a public health consortium, the Indian health care system, which includes the IHS, tribes and tribal organizations, and urban Indian health programs, has the opportunity to be a model for the care of chronic kidney disease. To do so, we must build the care of patients with kidney disease into our system so that nurses, dietitians, pharmacists, and other non-physician health providers—not just nephrologists and primary care physicians—are involved in implementing appropriate care.

K/DOQI—The NKF evidence-based clinical practice guidelines

Chronic kidney disease is under-diagnosed and under-treated, in part, because people do not know what it is. Prior to the NKF guidelines, agreement on how to classify the stages of chronic kidney disease did not exist. The NKF concluded that uniform definitions of terms and stages

would improve communication between patients and providers, enhance public education, promote dissemination of research results, and enhance conduct of clinical research.

The following is a summary of the guidelines. To read the guidelines in their entirety, visit the NKF website at www.kidney.org.

Guideline 1. Definition and stages of kidney disease
Adverse outcomes of chronic kidney disease can often be prevented or delayed through early detection and treatment. Earlier stages of chronic kidney disease can be detected through routine laboratory measurements. The presence of chronic kidney disease should be established, based on presence of kidney damage and level of kidney function (glomerular filtration rate [GFR]), irrespective of diagnosis.

The NKF proposes that we discontinue the use of the term "renal" and exclusively use the more widely understood word "kidney." According to the clinical practice guidelines, the official definition of kidney disease is:

- Kidney damage present for at least three months, as defined by structural or functional abnormalities of the kidney, with or without decreased GFR, manifested by either pathological abnormalities or markers of kidney damage, including abnormalities in the composition of the blood or urine or abnormalities in imaging tests.
- GFR of less than 60 mL/min/1.73m^2 for at least three months, with or without kidney damage.

Note that the level of GFR is widely accepted as the best overall measure of kidney function in health and disease. GFR is the best measure of the kidneys' ability to filter blood. The NKF defines each stage of chronic kidney disease based on GFR, not creatinine measures.

Among patients with chronic kidney disease, the stage of disease should be assigned based on the level of kidney function, irrespective of diagnosis, according to the clinical practice guidelines classification described in Table 1.

Table 1. Stages and prevalence of chronic kidney disease, ages 20 years and older

Stage	Description	GFR (mL/min/1.73m^2)	Prevalence*	
	At increased risk	≥90 (with CKD risk factors)	N(1000s)	%
1.	Kidney damage with normal or ↑ GFR	≥90	5,900	3.3
2.	Kidney damage with mild ↓ GFR	60-89	5,300	3.0
3.	Moderate ↓ GFR	30-59	7,600	4.3
4.	Severe ↓ GFR	15-29	400	0.2
5.	Kidney Failure	<15 (or dialysis)	300	0.1

*Data for Stages 1-4 from NHANES III (1988-1994)[1]. Population of 177 million adults age ≥20 years. Data for Stage 5 from USRDS (1998)[2] include approximately 230,000 patients treated by dialysis, and assume 70,000 additional patients not on dialysis. GFR estimated from serum creatinine using MDRD Study equation based on age, gender, race and calibration for serum creatinine. For stages 1 and 2, kidney damage estimated by spot albumin-to-creatinine ratio >17 mg/g in men or >25 mg/g in women on two measurements

Guideline 2. Evaluation and treatment

Preparation for kidney replacement therapy (dialysis and transplantation), as well as vascular access care, should be initiated when the estimated GFR declines to <30 mL/min/1.73 m^2. Table 2 describes the clinical action plan for each stage of the disease.

Table 2. Chronic kidney disease: A clinical action plan

Stage	Description	GFR (mL/min/1.73m^2)	Action*
	At increased risk	≥90 (with CKD risk factors)	Screening Chronic kidney disease risk reduction
1.	Kidney damage with normal or ↑ GFR	≥90	Diagnosis and treatment Treatment of comorbid conditions, slowing progression, Cardiovascular disease risk reduction
2.	Kidney damage with mild ↓ GFR	60-89	Estimating progression
3.	Moderate ↓ GFR	30-59	Evaluating and treating complications
4.	Severe ↓ GFR	15-29	Preparation for kidney replacement therapy
5.	Kidney Failure	<15 (or dialysis)	Replacement (if uremia present)

Chronic kidney disease is defined as either kidney damage or GFR <60 mL/min/1.73 m^2 for ≥3 months. Kidney damage is defined as pathologic abnormalities or markers of damage, including abnormalities in blood or urine tests or imaging studies.
* Includes actions from preceding stages.

Guideline 3. Individuals at increased risk for chronic kidney disease
Individuals at increased risk for chronic kidney disease should be tested at the time of a health evaluation to determine if they have chronic kidney disease. This includes individuals with:

- Diabetes
- Hypertension
- Autoimmune diseases
- Systemic infections
- Exposure to drugs or procedures associated with acute decline in kidney function
- Recovery from acute kidney failure
- Age 60 years and older
- Family history of kidney disease
- Reduced kidney mass (includes kidney donors and transplant recipients)

Measurements should include:

- Serum creatinine for estimation of GFR
- Assessment of proteinuria
- Urinary sediment or urine dipstick for red blood cells and white blood cells

Guideline 4. Estimation of GFR
Estimated GFR should be the parameter used to evaluate the level of kidney function.

- The level of GFR should be estimated from prediction equations that take into account the serum creatinine concentration and some or all of the following variables: age, gender, race, and body size. The following equations provide useful estimates of GFR:
  - In adults, the MDRD Study and Cockcroft-Gault equations. These equations have been in use for many years. The Cockcroft-Gault equation requires the patient's age, weight, serum creatinine, and gender. The MDRD equation requires only age and gender. However, the MDRD equation has not been validated in AI/ANs.
  - In children, the Schwartz and Counahan-Barratt equations. These equations may be more accurate, but have not been validated in AI/ANs.
- The serum creatinine concentration alone should not be used to assess the level of kidney function.
- Clinical laboratories should report an estimate of GFR using a prediction equation, in addition to reporting the serum creatinine measurement.

- Autoanalyzer manufacturers and clinical laboratories should calibrate serum creatinine assays using an international standard.
- Measurement of creatinine clearance using timed urine collections does not improve the estimate of GFR over that provided by prediction equations. A 24-hour urine sample provides useful information for:
  - Estimation of GFR in individuals with exceptional dietary intake (e.g., vegetarian diet, creatine supplements) or muscle mass (e.g., amputation, malnutrition, muscle wasting)
  - Assessment of diet and nutritional status
  - The need to start dialysis

Guideline 5. Assessment of proteinuria

The ratio of protein or albumin to creatinine in spot urine samples should be monitored in all patients with chronic kidney disease. Normal individuals usually excrete very small amounts of protein in the urine. Persistently increased protein excretion is usually a marker of kidney damage. The excretion of specific types of protein, such as albumin or low molecular weight globulins, depends on the type of kidney disease that is present.

Increased excretion of albumin is a sensitive marker for chronic kidney disease due to diabetes, glomerular disease, and hypertension. Increased excretion of low molecular weight globulins is a sensitive marker for some types of tubulointerstitial disease. In this guideline, the term "proteinuria" refers to increased urinary excretion of albumin, other specific proteins, or total protein; "albuminuria" refers specifically to increased urinary excretion of albumin. "Microalbuminuria" refers to albumin excretion above the normal range but below the level of detection by tests for total protein. Guidelines for detection and monitoring of proteinuria in adults and children differ because of differences in the prevalence and type of chronic kidney disease.

Guidelines for Adults and Children:

- Under most circumstances, untimed ("spot") urine samples should be used to detect and monitor proteinuria in children and adults.
- It is usually not necessary to obtain a timed urine collection (overnight or 24-hour) for these evaluations in either children or adults.
- First morning specimens are preferred, but random specimens are acceptable if first morning specimens are not available.
- In most cases, screening with urine dipsticks is acceptable for detecting proteinuria.
- Standard urine dipsticks are acceptable for detecting increased total urine protein.
- Albumin-specific dipsticks are acceptable for detecting albuminuria.
- Patients with a positive dipstick test (1 1 or greater) should undergo confirmation of proteinuria by a quantitative measurement (protein-to-creatinine ratio or albumin-to-creatinine ratio) within three months.

- Patients with two or more positive quantitative tests temporally spaced by one to two weeks should be diagnosed as having persistent proteinuria and undergo further evaluation and management for chronic kidney disease as stated in Guideline 2.
- Monitoring proteinuria in patients with chronic kidney disease should be performed using quantitative measurements.

Specific Guidelines for Adults:

- When screening adults at increased risk for chronic kidney disease, albumin should be measured in a spot urine sample using either:
  - Albumin-specific dipstick
  - Albumin-to-creatinine ratio
- When monitoring proteinuria in adults with chronic kidney disease, the protein to-creatinine ratio in spot urine samples should be measured using:
  - Albumin-to-creatinine ratio
  - Total protein-to-creatinine ratio is acceptable if albumin-to-creatinine ratio is high

Specific Guidelines for Children *without* Diabetes:

- When screening children for chronic kidney disease, total urine protein should be measured in a spot urine sample using either:
  - Standard urine dipstick
  - Total protein-to-creatinine ratio
- Orthostatic proteinuria must be excluded by repeat measurement on a first morning specimen if the initial finding of proteinuria was obtained on a random specimen.
- When monitoring proteinuria in children with chronic kidney disease, the total protein-to-creatinine ratio should be measured in spot urine specimens.

Specific Guidelines for Children *with* Diabetes:

- Screening and monitoring of post-pubertal children with diabetes of five or more years of duration should follow the guidelines for adults.
- Screening and monitoring other children with diabetes should follow the guidelines for children without diabetes.

Guideline 6. Markers of chronic kidney disease other than proteinuria
Markers of kidney damage in addition to proteinuria include abnormalities in the urine sediment and abnormalities on imaging studies. Constellations of markers define clinical presentations for some types of chronic kidney disease. New markers are needed to detect kidney damage that occurs prior to a reduction in GFR in other types of chronic kidney diseases.

Guideline 7. Association of level of GFR with hypertension
Blood pressure should be monitored in all patients with chronic kidney disease. High blood pressure should be evaluated and treated according to established guidelines, such as those of the American Diabetes Association.

Guidelines 8–12
Patients with GFR <60 mL/min/1.73 m^2 should be evaluated and treated for complications of decreased GFR. This includes measurement of:

- Anemia (hemoglobin)
- Nutritional status (dietary energy and protein intake, weight, serum albumin, serum total cholesterol)
- Bone disease (parathyroid hormone, calcium, phosphorus)
- Functioning and well-being (questionnaires)

Guideline 13
Estimated GFR should be monitored annually in patients with chronic kidney disease, and more frequently in patients with:

- GFR <60 mL/min/1.73 m^2
- Fast GFR decline in the past (≥4 mL/min/1.73 m^2)
- Risk factors for faster progression
- Ongoing treatment to slow progression
- Exposure to risk factors for acute GFR decline

Guideline 14
Individuals with diabetic kidney disease are at higher risk of diabetic complications, including retinopathy, cardiovascular disease, and neuropathy. They should be evaluated and managed according to established guidelines.

Guideline 15
Individuals with chronic kidney disease are at increased risk of cardiovascular disease. They should be considered in the highest risk group for evaluation and management according to established guidelines.

Clinical performance measures

The NKF also developed clinical performance measures. Providers should meet each performance measure for every diabetic patient and for every AI/AN who has a family member with diabetes. Table 3 displays the clinical performance measures.

Table 3. Clinical practice guidelines and performance measures

Guideline	Subject	Clinical Performance Measures?
1	Stages of Chronic Kidney Disease	
2	Evaluation and Treatment	Yes[a]
3	Individuals at Increased Risk for Chronic Kidney Disease	Yes[a]
4	Estimation of GFR	Yes[a]
5	Assessment of Proteinuria	Yes[a]
6	Markers of Kidney Damage Other than Proteinuria	
7	High Blood Pressure	Yes[b]
8	Anemia	Yes[a]
9	Malnutrition	Yes[a]
10	Bone Disease and Disorders of Calcium and Phosphorus Metabolism	Yes[a]
11	Neuropathy	
12	Functioning and Well-Being	Yes[a]
13	Loss of Kidney Function	Yes[b,c]
14	Diabetic Complications	Yes[b]
15	Cardiovascular Disease	Yes[a,b,c]

[a] Recommended for development of clinical performance measures based on CKD Guidelines.

[b] Recommended for development of clinical performance measures based on other guidelines such as those produced by JNC, ADA.

[c] Treatment recommendations in Guidelines 13 and 15 cannot be recommended for development of clinical performance measures, since such measures by definition depend on systematic review of the evidence, which was not performed for these guidelines.

Outcomes

An outcome that we need to measure is the number of patients on dialysis. You can obtain this number by consulting the U.S. Renal Data System (USRDS), which is considered the best chronic disease registry in the world. The registry can tell you who is identified as AI/AN at each dialysis unit. However, in some IHS Areas, racial misclassification may pose a problem. To help deal with this problem, you can contact the ESRD Network for your region. Although the networks cannot provide you with individually identified information, they can tell you how many AI/ANs in a particular county or zip code began dialysis, how many are on dialysis, how many were treated, and what their gender is.

Recommendations

In addition to implementing the NKF clinical practice guidelines, the workgroup developed several recommendations:

- Enhance the Resource and Patient Management System (RPMS) laboratory package so that it will provide a calculated GFR when you order a creatinine.
- Promote efforts by our clinical labs to standardize creatinine measurement calibration.
- Build performance measures based on K/DOQI standards into our patient monitoring and documentation.
- Develop relationship with regional ESRD Networks for data sharing and outcome measurement.

Numerator Workgroup

Eye Care

Mark Horton, OD, MD, Moderator
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Indian Health Service

Background

The effects of diabetes spare no portion of the eye, from the cornea to the optic nerve. The workgroup discussed that, given the dimension of unmet need in this area, the Indian Health Service (IHS) should prioritize its efforts on diabetic retinopathy to focus on annual diabetic retinopathy exams, and applying the standards of the Early Treatment Diabetic Retinopathy Study (ETDRS) to prevent blindness. Once the IHS makes significant inroads into diabetic retinopathy, we can begin to increase special attention on other diabetes-related events that occur in the eye.

The two major stages of diabetic retinopathy-are non-proliferative diabetic retinopathy, and proliferative diabetic retinopathy. Macular edema is a third major category that can exist in either of these stages.

- *Non-proliferative diabetic retinopathy*, also known as background retinopathy, is characterized by retinal microaneurysms, intraretinal hemorrhages, retinal ischemia with arterial-venous shunts, and leakage of fluid with exudates formation in the retina. Vision loss is generally not apparent to the patient unless macular edema is present.
- *Proliferative diabetic retinopathy* is characterized by new blood vessel growth in the retina and vitreous. These blood vessels break and bleed into the vitreous (i.e., the clear substance that fills the center portion of the eye), causing cloudiness and impaired vision. In addition, the new blood vessels can cause scar tissue development, which, in turn, can lead to retinal detachment and blindness.
- *Macular edema* is characterized by fluid collection in the macula (i.e., a tiny area in the center of the retina). Since this is the only area in the retina with the capacity for 20/20 vision, fluid accumulation results in a loss of vision.

Recommendation #1: Develop a system to track eye care that is referred off-site

When a patient is referred off-site for eye care (e.g., when an optometrist sends a patient to an ophthalmologist for a final diagnosis of level of diabetic retinopathy), how can we determine if the patient made the off-site visit, if they received a comprehensive eye exam, and if they received treatment? To capture this information, each site should develop a system to track offsite eye care. Workgroup participants made several suggestions, including requiring a proof of receivables and linking to payment; directly following-up with patients for whom the site does not have information about their off-site visit; and asking patients to sign releases of information to allow the clinic to follow-up with off-site providers. It is imperative that sites do not accept

patient self-reports as proof that they received a comprehensive diabetic eye exam, which includes dilation.

Recommendation #2: Refer to "diabetic eye care" as "diabetic retinal care"

As stated above, diabetes eye care encompasses every part of the eye, from the tear layer to the optic nerve. However, our current focus is on the retina, which is appropriate because diabetic retinopathy is the leading cause of blindness in this group. The IHS Diabetes Care and Outcomes Audit (diabetes audit) criteria currently captures people who have had their retina examined, but it excludes conjunctivitis, corneal disease, and other diabetes-related eye problems. For these reasons, we should refer to "diabetic eye care" as "diabetic retinal care."

Recommendation #3: Exclude patients who are blind from the denominator and exclude patients who refuse a comprehensive eye exam

The diabetes audit includes a YES/NO question as to whether a patient with diabetes received a comprehensive eye exam. For patients who are blind, the answer must be "no" because it was not possible to give them an eye exam, similar to amputees who cannot receive a foot exam. The workgroup participants believe that they should not be penalized for being unable to provide an eye exam to those who are blind in both eyes, and that those patients should be excluded from the denominator. The workgroup participants also felt that patients who refused to have a comprehensive eye exam should be excluded from the denominator as well. Dr. Horton, however, disagreed saying that they should be counted because they will likely end up with complications and the information is important to direct programs and target interventions. As a secondary recommendation, the workgroup recommended that the percentage of refusals be reported along with the overall rate of eye exams.

Recommendation #4: Develop a standard definition for blindness

For the purposes of the diabetes audit, how is it determined if someone is blind or suffers from serious vision loss? A definition of blindness is crucial for determining if a clinic will intervene. If you define someone who still has some remaining vision as being blind, the opportunity to intervene may be lost. To develop a standard definition for blindness, the workgroup recommended that the IHS Eye Care Committee meet to develop a standard definition of blindness for the IHS.

Recommendation #5: Count interventions as the measure of success

We have excellent research that shows what happens to vision when diabetic retinopathy is treated with laser photocoagulation, the only established treatment. The current outcome measure is a report of a person's vision. However, Dr. Horton argued that the outcome measure should simply be a count of complete laser interventions since this is currently the only treatment option. The incidence of severe vision loss following treatment can be predicted by the ETDRS.

Numerator Workgroup

Foot Care

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Indian Health Service

Background: Factors that influence our data

Dr. Dannels provided the following recommendation from the 2002 American Diabetes Association Clinical Practice Recommendations: "Fast ulcers and amputations are a major cause of morbidity, disability, as well as emotional and physical costs for people with diabetes. Early recognition and management of independent risk factors for ulcers and amputations can prevent or delay the onset of adverse outcomes."

The workgroup discussed factors that influence the credibility and accuracy of foot care data:

- *Who is the provider?* We will obtain different information based on whether the provider who performs the foot exam is a family practice physician, a podiatrist, or a community health representative (CHR)
- *Are the data entered into the Resource and Patient Management System (RPMS)?*
- *How reliable are the data?* Is every provider in your facility documenting lower extremity exams in the same manner as a comprehensive foot exam?
- *Transportation*
- *Billing*. A large amount of staff time and energy is needed to determine who is and who is not eligible for federal benefits for health care
- *Foot exams vs. foot checks*
- *Patient buy-in*
- *Staff turnover, levels, and education*

Recommendation #1: Determine which conditions should be considered a deformity

Deformities are important to look for during a foot exam to identify problems early and to intervene. Deformities can be anything from hammertoes or bunions to amputations or joint resections. The workgroup recommended that we begin the process of coding for deformities by developing criteria for which conditions are considered a deformity.

Recommendation #2: Develop a reproducible exam protocol

We need to identify patients, convince them that they need a foot exam, and figure out how to develop a consistent foot exam that we can perform with *reliability* and *reproducibility*. In addition to collecting data that are currently meaningful, the protocol for a consistent foot exam should also collect data that will be meaningful in the future, thereby setting the stage for

conditions that we can focus on in the next five or ten years. The protocol should also include how we will ensure that data entry is consistent.

Recommendation #3: Add a field in RPMS for "Not a reliable exam"

The workgroup participants reported that the mental status of the patient can affect the reliability of the foot exam. The workgroup therefore recommended that a field in RPMS be added that allows providers to indicate if an exam was unreliable.

Recommendation #4: Develop a consistent electronic screening tool

A consistent electronic screening tool that can be translated in PCC + will provide the Indian Health Service with a common database. This tool would support efforts to enhance electronic data collection.

Numerator Workgroup

Patient Education Documentation

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Patient education documentation background

When documenting patient education in a medical chart, the majority of Indian Health Service (IHS) providers write a narrative of their patient education activities. Alternatively, providers could document patient education by using the IHS Patient and Family Education Protocols and Codes. These protocols and codes were developed to standardize the documentation of patient education. Currently, a national committee that includes health care professionals meets annually to develop and update the protocols and codes for patient education topics. The manual of protocols and codes can be found at the IHS website (www.ihs.gov) under Health Education and National Patient Education Initiative.

The IHS Patient and Family Education Protocols and Codes are a method of documenting patient education on the Resource and Patient Management System (RPMS) Patient Care Component (PCC). The protocols and codes are the only documentation of patient education that is recognized throughout the IHS, and they meet Joint Commission on Accreditation of Healthcare Organizations (JCAHO) certification requirements. The protocols are written guidelines for education and contain the following elements:

- Outcomes to be achieved through education
- Standards to be followed when educating
- The code to use to document the type of education that was provided

Figure 1 displays a sample of a page on hypertension from the Patient Education manual. The standards that are displayed in the sample are the points that you will need to cover when educating a patient on hypertension complications. You will meet JCAHO and IHS standards if you teach at least half of the standards. Like ICD-9 codes and CPT codes, you will use the patient education codes for documentation and reimbursement. In addition, you will use the patient education codes for JCAHO standards, Government Performance and Results Act (GPRA) indicators, ORYX indicators, and the cardiovascular indicator for the IHS. More importantly, the codes are used to help direct our primary prevention efforts through education.

PATIENT EDUCATION PROTOCOLS
***Example:* HYPERTENSION COMPLICATIONS**
from the Protocols Manual

Code: HTN-C Hypertension Complications

Outcome: The patient will verbally summarize the complications of uncontrolled hypertension.

Standards:

1. Explain that arteriosclerosis and atherosclerosis impede blood flow through the circulatory system.

2. Explain that heart attacks may result from the heart having to work harder to pump blood through congested and hardened arteries.

3. Explain that blindness may result from injured blood vessels in the eye.

4. Explain that strokes may result from injured blood vessels in the brain.

5. Explain that circulatory complications eventually impair the ability of the kidneys to filter out toxins

Figure 1. Sample page from the IHS Patient and Family Education Protocols and Codes

To document patient education, you should follow the five steps outlined below. Figure 2 illustrates each of these steps, and Figure 3 illustrates how you can document each of these five steps in the chart.

- Disease state, condition, or system being addressed (e.g., diabetes, hypertension, cardiovascular disease, lice, asthma, or breastfeeding). You can use the ICD-9 code or the patient education code mnemonic (see below).
- Specific education topic or modifier. You have 17 choices (e.g., complications, disease process, procedures, test, home management, exercise, nutrition, etc.), which will never change.
- Level of patient or family understanding of the material. This is not a direct indication of how well you teach. Rather, this step gauges if the patient learned something and how well they understood the information that you presented. You will ask them to demonstrate that they understand the material.
- Time spent providing the education.
- Initials of the health care provider who provided the education.

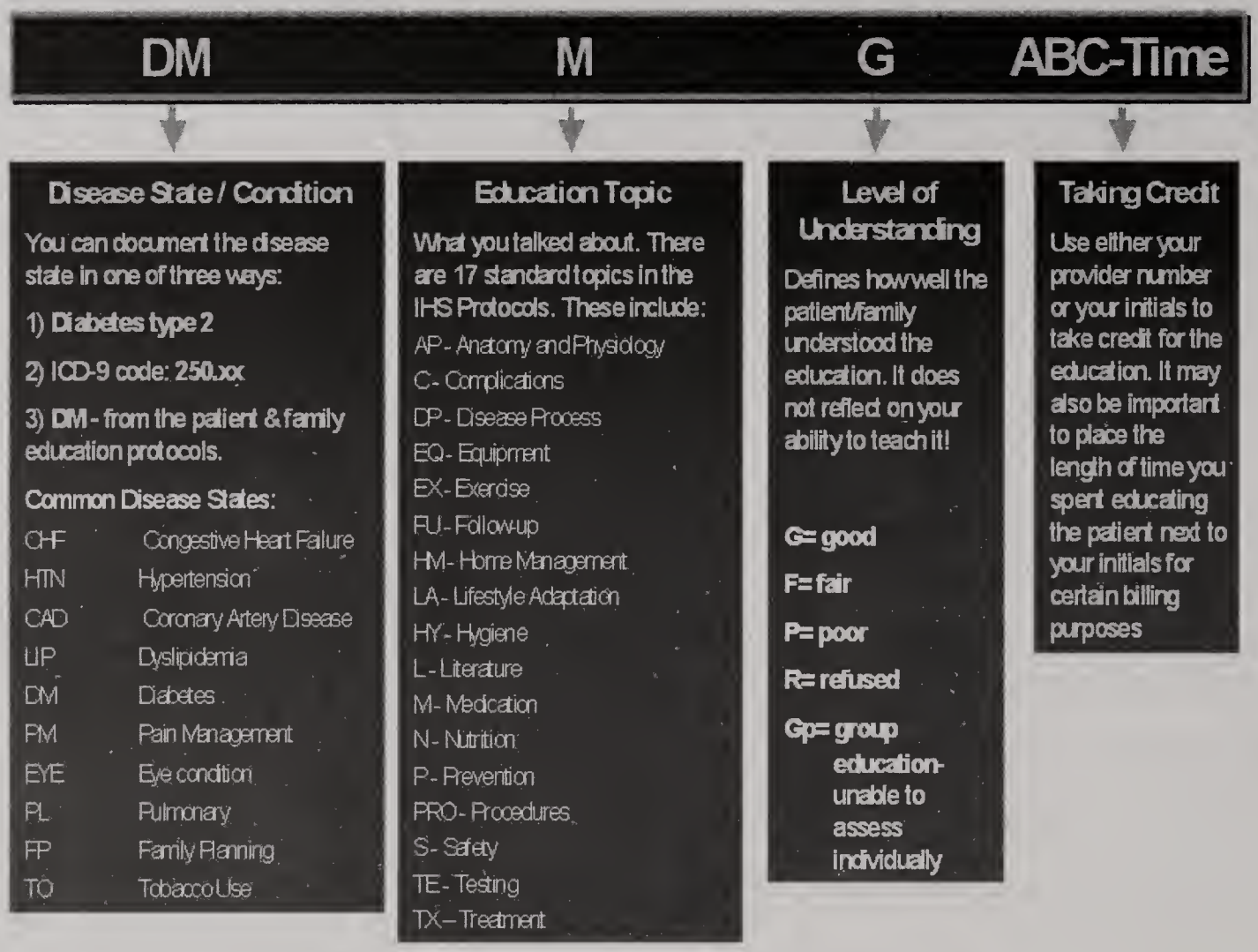
DM
M
G
ABC-Time
Disease State / Condition
You can document the disease state in one of three ways:
1) Diabetes type 2
2) ICD-9 code: 250.xx
3) DM - from the patient & family education protocols.
Common Disease States:
CHF Congestive Heart Failure
HTN Hypertension
CAD Coronary Artery Disease
LIP Dyslipidemia
DM Diabetes
PM Pain Management
EYE Eye condition
PL Pulmonary
FP Family Planning
TO Tobacco Use
Education Topic
What you talked about. There are 17 standard topics in the IHS Protocols. These include:
AP - Anatomy and Physiology
C - Complications
DP - Disease Process
EQ - Equipment
EX - Exercise
FU - Follow-up
HM - Home Management
LA - Lifestyle Adaptation
HY - Hygiene
L - Literature
M - Medication
N - Nutrition
P - Prevention
PRO - Procedures
S - Safety
TE - Testing
TX – Treatment
Level of Understanding
Defines how well the patient/family understood the education. It does not reflect on your ability to teach it!
G= good
F= fair
P= poor
R= refused
Gp= group education- unable to assess individually
Taking Credit
Use either your provider number or your initials to take credit for the education. It may also be important to place the length of time you spent educating the patient next to your initials for certain billing purposes

Figure 2. The five steps for documenting patient and family education

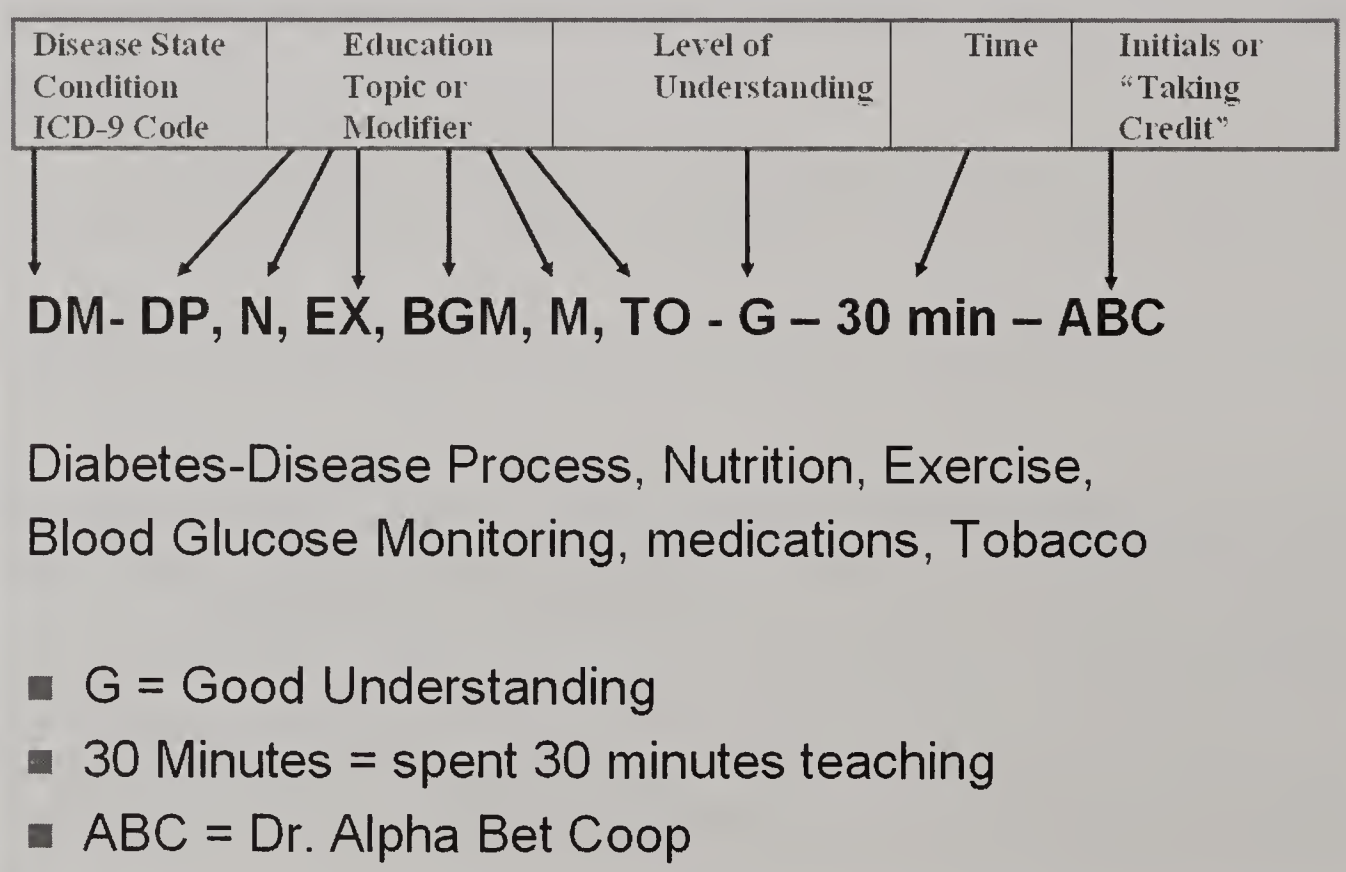
Disease State Condition ICD-9 Code
Education Topic or Modifier
Level of Understanding
Time
Initials or "Taking Credit"
DM- DP, N, EX, BGM, M, TO - G – 30 min – ABC
Diabetes-Disease Process, Nutrition, Exercise,
Blood Glucose Monitoring, medications, Tobacco
G = Good Understanding
30 Minutes = spent 30 minutes teaching
ABC = Dr. Alpha Bet Coop

Figure 3. Illustration of how you can document patient and family education in the medical chart

Patient education documentation for diabetes

Currently, the IHS uses 15 codes to document education related to diabetes. The following table outlines each of these codes.

Table 1. Education topics and modifiers for diabetes

Education Topic or Modifier	Code
Disease Process	DP
Complications	C
Nutrition	N
Lifestyle Adaptations	LA
Exercise	EX
Tobacco	TO
Blood Glucose Monitoring	BGM
Equipment	EQ
Foot Care	FTC
Home Management	HM
Kidney Disease	KD
Prevention	P
Pain Management	PM
Wound Care	WC
Follow-up	FU

The IHS National Diabetes Program has developed a new diabetes curriculum that has 16 protocols and codes outlined in Table 2. The Patient and Family Education Protocols and Codes Committee worked with the IHS National Diabetes Program to develop new codes and protocols for the curriculum. For nearly all of the protocols, the IHS National Diabetes Program has developed a new concept that will allow you to track *patient goals* based on the education that they received. For example, if you talk to a patient about the need to participate in physical activity, you will cover seven education standards with the patient. You would then ask the patient what their goals are with respect to physical activity. If the patient responds that he or she will try to walk five times a week, you will document that the patient has set a behavior goal on the medical form by including the mnemonic "GS" in your patient education documentation (e.g., DM-PA-G-time-**GS**-your initials). The next time the patient comes into the clinic, the provider will see the mnemonic "GS" under the patient education section, which will prompt him or her to ask the patient if he or she met the goal. You would then indicate that the patient met the goal with a "GM" or did not meet the goal with a "GNM" in the patient education documentation for that visit.

The new diabetes curriculum also includes six new gestational diabetes codes. These codes are listed in Table 3.

Table 2. Education topics and modifiers for the new diabetes curriculum

Education Topic or Modifier	Code
Disease Process	DP
Mind, Spirit, and Emotion	MSE
Making Healthy Changes	BG
Physical Activity	PA
Medications and Oral Pills	MP
Insulin	IN
Blood Glucose Monitoring	BGM
Know Your ABCs	ABC
Acute Complications	AC
Chronic Complications	CC
Foot Care	FTC
Nutrition	N
Planning for Pregnancy	PPC
Literature	L
Follow-up	FU
Wound Care	WC

Table 3. Education topics and modifiers for *gestational diabetes* in the new diabetes curriculum

Education Topic or Modifier	Code
Disease Process	DP
Nutrition	N
Complications	C
Blood Glucose Monitoring	BGM
Exercise	EX
Blood Glucose	BG

Issues to consider

- The IHS National Diabetes Program proposes that you must teach all of the standards in a protocol to claim that you have completed the patient education for that protocol. What are the implications if the IHS National Diabetes Program requires sites to teach all of the standards before claiming that they have completed a particular protocol?
- How should the IHS provide patients with general information on diabetes?
- The RPMS PCC data entry training module needs to provide direction on entering patient education.
- Who is going to teach the new protocols and codes for the new diabetes curriculum to staff?
- For the third party billing package in RPMS, we need to develop an entry point area for patient education reimbursement—at least for third party insurers (not Medicare and Medicaid).
- The new diabetes curriculum and codes will have a numerical number mixed in with the text. Is this possible?
- How can we foster an understanding of how Medical Nutrition Therapy documentation reflects the protocols and codes?
- For reimbursement, we need to be able to document education by Certified Diabetes Educators (CDE) versus non-CDEs and nutrition education by health providers versus registered dietitians.
- We need to develop strategies and solutions to help health providers remember the protocols and codes. One suggestion is to develop a cheat card for the protocols that are the most heavily used.
- The IHS has proposed eliminating older codes. The workgroup recommended that the older codes be phased out, but remain in the system in an inactive state. Although this system will prevent sites from using the old codes, it will allow sites to access information using the old codes and obtain historical information.
- IHS statistics indicate that the only providers who consistently document patient education are pharmacists. How can we engage other providers to participate in documenting patient education?
- The current RPMS diabetes package needs to be updated to eliminate redundant choices and to reflect new education:
  - Eliminate the word "diet," and use the word "nutrition."
  - Some entries, such as "wellness," are vague and confusing. Currently, there is neither a diabetes wellness protocol nor code.

Denominator Workgroup

Denominator Workgroup: Understanding the Criteria for Who Is (or Is Not) Counted when Describing Diabetes Prevalence, Performing a Diabetes Audit, or Establishing a Diabetes Registry

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Background

In strict definitional terms, the denominator is the part of a fraction that indicates the number by which the numerator will be divided. For epidemiologic purposes, an accurate denominator allows the calculation of a reliable rate of a particular disease or condition within a population. Although the calculation is usually straightforward, knowing whom to include in the denominator population is frequently less clear. This brings a second, more abstract definition of denominator into discussion. In this more abstract definition, a denominator is defined as "something shared or held in common; a standard." The participants of the denominator workgroup discussed and, to some extent, came to a common understanding of three unique and different populations of patients who make up three different, but commonly used, denominators: 1) the national prevalence population; 2) the population for the Indian Health Service (IHS) Diabetes Care and Outcomes Audit (diabetes audit); and 3) the diabetes registry population.

Topic #1: Who is counted when describing diabetes prevalence?

The IHS uses prevalence for many purposes, including reporting disease burden to outside agencies and Congress, developing funding formulas, evaluating programs and comparing interventions, and assessing workloads. These purposes require that prevalence be applicable among local levels, such as particular Areas, tribes, or regions, and provide a consistent overall snapshot of a disease or condition.

When used for calculating diabetes prevalence, the most consistent and standard population is the IHS user population. This population includes the following individuals:

- The individuals must be American Indian or Alaska Native (AI/AN) as defined in the Indian Health Care Improvement Act.
- The individuals must be living and have at least one registered visit within a three-year time period. Although somewhat arbitrary, use of this historical three-year definition provides consistency over time, allows for the eventual exclusion of deceased individuals who are not documented as such, and is a reasonable compromise between too limited or too lenient restrictions on health care use of a person in the community.
- The individual is counted only one time. The process used to ensure that each individual is counted only once is called unduplication. Although the unduplication process does not eliminate any registrant, it combines different registration and clinical data from

different locations into a single user count. For example, for an individual who is registered at five different locations, the unduplication process combines the data from each of the five sources into a single user who is counted only once. The registrant is then assigned to one location that is consistent with the best available information on his or her community of residence. Although individuals or their data are not lost in this process, any one community or facility may lose (or gain) individuals based on the assignment of community of residence.

Use of this consistent population allows for a calculation of prevalence that is highly accurate and reasonably comparable between Areas and at the national level. Currently, this population includes approximately 1.2 million AI/ANs.

The workgroup noted two major problems with estimating the denominator for diabetes prevalence calculations. First, while most sites recognize the importance of data, many sites (particularly urban sites and sites that do not use the Resource and Patient Management System [RPMS]), have experienced technical difficulty in exporting their data for inclusion in prevalence calculations. Second, the IHS is not able to obtain data on the roughly 800,000 AI/ANs who have not been seen at an IHS, tribal, or urban (I/T/U) facility and therefore have not been counted. Are these individuals different from the individuals who have been seen at an I/T/U facility? Do they have more or less diabetes? Answers to these questions would help the level of confidence in estimating the burden and prevalence rates of diabetes.

The workgroup recommended that I/T/U facilities educate their stakeholders (e.g., community leaders, administrators, etc.) on the process involved in calculating diabetes prevalence. By educating these stakeholders, they are likely to become advocates for improved data collection. In addition, the workgroup discussed how a state-of-the-art national data warehouse, which would include more complete urban data, will assist in defining denominators and numerators.

Topic #2: Diabetes audit denominator

Since 1986, the diabetes audit has been the most important measure of the quality of care for AI/ANs with diabetes. Over the years—through trial and error, with input from providers working in I/T/U facilities, and with the consensus of Area Diabetes Consultants—a set of explicit instructions have been developed to help sites determine the individuals who should be included in or excluded from the diabetes audit. The instructions aim to include as many individuals as possible to obtain an accurate picture of diabetes at the community level. However, they also aim to exclude people who would not be appropriate to include because they do not or could not receive their care from the facility in which the diabetes audit is performed.

While the instructions are as descriptive as possible, different facilities have different interpretations of the instructions. To resolve the differences in interpretation, the instructions are revised as necessary. For example, in 2002, for the first time the explicit instruction that the patient "must have been seen in the past year" was added. Thus, while inclusion and exclusion criteria have been modified slightly over the years, the core principles have remained steady, allowing for year-to-year monitoring and comparisons between facilities and Areas. The current inclusion and exclusion criteria are summarized in Table 1.

Table 1. 2002 IHS Diabetes Care and Outcomes Audit inclusion and exclusion criteria

Inclusion Criteria: Include patients who...	**Exclusion Criteria: Exclude patients who...**
Attend regular clinics or diabetes clinics	Have not had at least one visit during the past 12 months
Refuse care or have special motivational problems (e.g., alcoholism)	Receive primarily referred or contract care, paid by the IHS
Are not attending clinic, but you do not know if they have moved or have found another source of care	Have arranged other medical care, paid with non-IHS funds
	Receive their primary care at another I/T/U facility
	Live and receive care in a jail
	Live and receive care in a nursing home
	Attend a dialysis unit (if on-site dialysis unit is unavailable)
	Have gestational diabetes
	Have impaired glucose tolerance only
	Have moved either permanently or temporarily
	You are unable to contact, defined as three tries in 12 months
	Have died

With the increasing interest in automating the diabetes audit by utilizing data from RPMS (i.e., the electronic diabetes audit), it has become important to know how to identify inclusion and exclusion criteria available in RPMS. For example, RPMS does not include fields that indicate that a patient is receiving their care elsewhere or is currently incarcerated and not eligible for inclusion in the diabetes audit. In April 2001, the IHS identified criteria to identify patients who should be included in the electronic diabetes audit. These criteria are:

- Age 19 years or older
- At least two diabetes-related encounters ever (any clinic and any provider)
- At least one encounter at the given IHS or tribal facility in a "primary care clinic" with a "primary care provider" with a "purpose of visit" of diabetes within the previous year
- A current community of residence that is within the given Service Unit's service delivery area, as defined in the standard code tables
- Absence of a creatinine value of 5.0 mg/dl or greater

Topic #3: Diabetes registries

A diabetes registry is a system to track a facility's patients who have diabetes. The systems used to develop and maintain a diabetes registry vary widely—from a simple box of 3" x 5" cards to an electronic registry in RPMS. In every type of registry, patients are often coded by their status, such as active (e.g., patients who receive their primary diabetes care at your clinic), transient (e.g., patients who use your clinic, but not for diabetes care), inactive (e.g., patients who do not regularly use your clinic), etc. Because the types of registries are varied, each facility may have different definitions for each status. For example, one clinic may consider a patient active if they have been seen at the clinic once in the last 12 months, whereas another clinic may consider a patient active if they have been seen at least once in the last 18 months. Sites are not using the same definitions for these registry statuses, and therefore do not include or exclude the same groups of people from the diabetes audit.

While having consistent criteria for the diabetes registries might provide the ability to compare facilities, the wide variety of services provided at each facility would make common definitions unlikely to meet the needs of the local diabetes care team. Furthermore, the major purpose of the diabetes registry is to be a useful tool for diabetes care teams at the local level.

General workgroup discussion

The workgroup provided an opportunity for many ideas and issues to be discussed. The following were selected as being particularly common to the group:

- Although software has been developed to perform automated data retrievals, the different levels of implementation and variation that exist in local processes and patient populations remain as challenges.
- Many facilities do not have the automation capabilities at this time or they have difficulty in finding the guidance needed to obtain the equipment and training. Thus, there is concern about losing a lot of information from tribes who for various reasons could not develop a diabetes registry or participate in the diabetes audit.
- Although diabetes registries play an important role, registry development requires resources, training, skills, and technical assistance. We have to take this message back to our communities and educate them on the importance of a registry in the development of good diabetes care at the local level.
- A major frustration of diabetes teams is experienced when they share their data with their tribal health boards, communities, and even clinic staff who do not have any statistics training or education. The diabetes teams have experienced difficulty convincing these stakeholders that the data are representative of the care that the sites are providing for the *entire* patient community.
- It is important that communities feel that data processes accurately reflect and include them. One workgroup member commented that good customer service is the key to working with communities on these issues.
- Some sites provide care of the non-AI/AN spouses of AI/AN patients. Therefore, some sites include non-AI/AN patients in their diabetes registry since they are providing diabetes care to those patients. However, this care is not reflected in the diabetes audit.

Conclusion and Conference Summary

Conclusion and Conference Summary

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Measuring Diabetes Care: Improving Data Quality and Data Use in American Indian and Alaska Native Communities concluded with a brief recap of the issues facing the current use of diabetes data. The purpose of this recap was to identify the issues in a concise manner that would stimulate further data quality evaluations and allow for further development of data solutions. The conference participants did not have a specific mandate to make recommendations, but these could be viewed as actionable items, or even expert suggestions.

Denominator issues

The denominator workgroup came to an understanding that the most important issue in identifying inclusion and exclusion criteria for a denominator is the importance of making sure that the criteria result in a meaningful group of patients. Currently, three different denominators exist to group patients into sets of patient populations. The criteria used to create these patient sets are different, and the purposes and uses of these populations are intended to be different.

The first denominator is the group of patients who make up the diabetes prevalence set. This is a denominator that creates an unduplicated set of patients for the purpose of estimating the prevalence of diabetes that is accurate over a very large area.

The second denominator is the group of patients who make up the Indian Health Service (IHS) Diabetes Care and Outcomes Audit (diabetes audit) set. This set creates a group of patients with standardized characteristics who are comparable from one facility to another. The purpose of this set is to compare clinical measurements between facilities or groups of facilities.

The third denominator is the diabetes registry denominator, which is a group of patients, defined by completely local criteria, that fulfills the need for local facilities to provide care and evaluate services in a way that is meaningful to them. It may or may not have characteristics in common with other facilities.

The denominator workgroup participants recognized the need to develop data education programs for stakeholders, such as tribal health boards, community members, and clinic staff. The purpose of these programs would be to describe the purpose of using different samples of patients to describe different aspects of diabetes. The workgroup also agreed that diabetes registries are extremely important for improving diabetes care. It is clearly a critical step for local empowerment. Finally, the workgroup recognized the need for customer service and technical assistance so that all sites can achieve similar results, whether it is with a manual diabetes audit or an electronic diabetes audit.

Numerator issues

The numerator workgroup focused on diabetes data issues covering several of the process and outcome measures for selected major complications of diabetes.

Chronic kidney disease

Equipped with a large body of scientific work and new recommendations by the National Kidney Foundation, clinical guidelines and specific measures and interventions will become the standard for ensuring the quality of care for people with chronic kidney disease. These new guidelines are applicable to the American Indian and Alaska Native (AI/AN) patient population, aim to improve the care of people with kidney disease by improving data definitions, stratify patients based on these improved classifications, and direct treatment based on that classification. A key feature of the new guidelines is the classification of patients with kidney disease into stages based on the patient's glomerular filtration rate (GFR). It will therefore be necessary for us to include GFR in our data system. Because kidney disease is a public health problem, the IHS has the opportunity to be a model for the care of the disease. The only way to improve care for kidney disease is to build our system around it so that nurses, dietitians, pharmacists care for it—not just nephrologists and primary care physicians.

Patient education

When we educate people, we empower them. Empowerment, in turn, can lead to improved health, which is the ultimate health outcome. The IHS Health Education Program and the IHS National Diabetes Program are working together to ensure standardization of documentation and coding protocols for patient education. Over the past several years the number of sites that are using patient education protocols and codes has greatly increased. However, many sites remain unaware of the protocols and codes. In addition, the two programs are working to ensure that the protocols and codes will be consistent with the new diabetes curriculum, which will meet the American Diabetes Association program recognition requirements. While this is in development, the current patient education protocols and codes allow for the documentation of diabetes, exercise, nutrition, and self-management education.

Foot care

In discussing the issues surrounding foot care among people with diabetes, a major point of discussion was the concern around the various criteria used to assess a complete foot exam. For example, both specific documentation of vascular and neurological exam and an evaluation by a podiatrist are used for evidence of a comprehensive foot exam. However, experience suggests that these two criteria may not necessarily correlate with an adequate examination. Therefore, the workgroup expressed interest in developing common forms for software applications, such as PCC +, as a way of coding the foot exam for both primary care providers and foot care specialists and ensuring that all exams meet the same minimum requirements. The National Council of Indian Health Podiatrists, the IHS National Diabetes Program, and other interested parties will need to communicate on these issues.

Another area of discussion surrounded the tracking of amputations as an outcome measure. The workgroup felt that this is a rather crude measure of quality. Furthermore, tracking amputations is complicated because it accounts for issues, such as risk status of the patient, the number of

amputations per person, and the pattern of sequential amputations that have occurred in order to know how to assess the meaning of an amputation.

Eye care
Similar to the discussion for foot care, the workgroup focused on the need for consistent documentation of the process of diabetic retinal examinations and the definition of the outcome measures. The workgroup recommended that consensus be reached about: 1) the definition for blindness; 2) whether to include or exclude individuals who are blind from the calculations of eye exam rates; and 3) how to use PCC + as a tool for making the elements of an eye exam more consistent. For the outcomes measure, the workgroup recommended tracking annual diabetic retinal exam rates and interventional events, such as laser therapy.

Cardiovascular disease
Cardiovascular disease was recognized as an extremely important issue because it is closely linked to diabetes and is the number one cause of death in the general U.S. population (both with and without diabetes) and among AI/ANs (both with and without diabetes). Although cardiovascular disease is a major cause of death, AI/ANs share a disproportionate burden of cardiovascular disease. Because of the major challenge posed by cardiovascular disease, the workgroup recommended extending the measurement of cardiovascular risks to people who do not have diabetes. Also, additional performance measures may be appropriate, such as effective and appropriate use of beta-blockers and physical activity.

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